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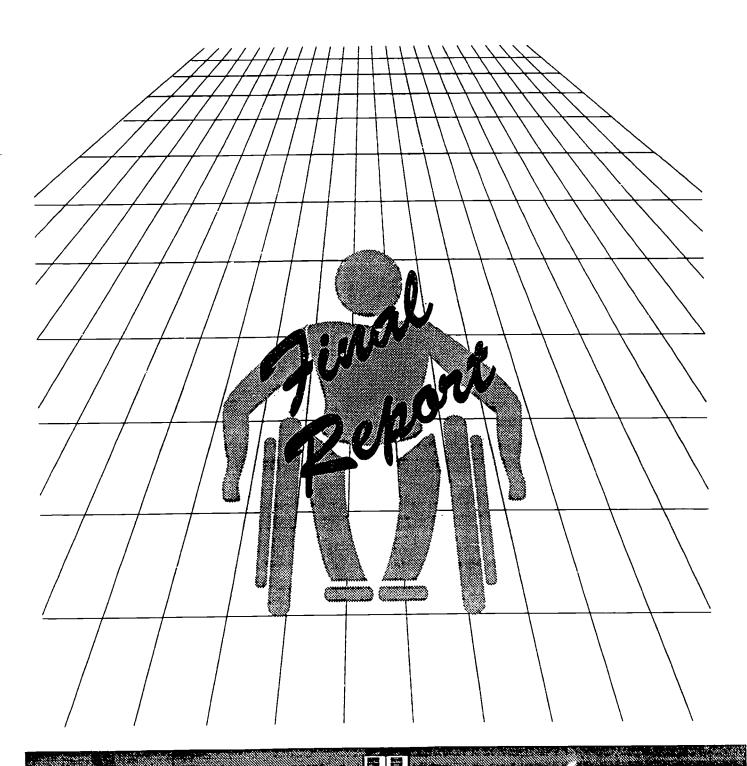
This final report presents results of a feasibility study and implementation plan concerning the establishment of a national assistive technology information and referral (ATI&R) network. The study explored the feasibility of establishing such a network from two perspectives: the current processes used to disseminate information about assistive technology and the needs of individuals who want access to assistive technology information. The study's five phases included use of an expert panel group, a key informant (N=541) survey, a needs survey of 4,298 consumers, 4 focus groups, and an examination of technical barriers to such a network. The study identified certain technical factors affecting the assistive technology information and program referral process including a lack of uniform definitions; a lack of uniform organizational structures; a lack of standards and/or requirements for personnel; a lack of consistent methods in data maintenance, verification, and updating; and a lack of effective outreach efforts. Extensive recommendations address: policy, coordination of AT I&R services, information management, staffing and I&R, outreach, and promoting AT I&R services. Six appendices present: a moderator's guide to regional focus groups; survey instrument protocols; glossaries and definitions used in the study; service taxonomy comparisons; a summary of technology-related information needs of providers and consumers; and a list of existing AT I&R organizational arrangements. (DB)

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The Feasibility & Desirability of Establishing a Nationwide Assistive Technology Information and Program Referral Network



Center for Developmental Disabilities
Department of Pediatrics
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Final Report

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PREFACE

n the Fall of 1991, the Center for Developmental Disabilities at the University of South Carolina received a contract to study "The Feasibility of Establishing a National Assistive Technology Information and Program Referral Network." The U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR), under the authority of Public Law 100-407, the "Technology Related Assistance for Persons with Disabilities Act of 1988", funded this study.

Six separate publications summarize the work of this study. Four of these publications report the major research findings. They focus on the establishment of a national network from the viewpoint of consumers and providers of technology-related information. Also included in these reports are recommendations and strategies for implementing research findings. The other two publications are resource tools. They consist of a Directory of Assistive Technology I&R Providers and an Annotated Bibliography of Assistive Technology I&R Related Publications.

The Feasibility Report provides a detailed discussion of the findings of the study and presents an implementation plan for establishing a national assistive technology information and referral network. The approach used to obtain the information for this report is a model for future research efforts. Additionally, the results can serve as a stimulus to coordinate action at the federal, state, and local levels to meet the information needs of individuals with disabilities. Improving access and availability of technology-related information to empower individuals with disabilities and their families is the ultimate goal.

This study has been both a demanding and rewarding experience for all those involved. The efforts of many individuals from across the nation were brought together to focus on assessing the technology-related information needs of consumers and the current state of AT I&R practices. It is our hope that in reading this report you will find that it is possible to affect change to meet the needs of consumers and improve the delivery of assistive technology information and referral services.



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ACKNOWLEDGEMENTS

his study could not have been possible without the efforts and contributions of many individuals. First, we would like to acknowledge the contributions of the Consumer Advisory Group, the Expert Panel Group, and the subcontractors of this study. Our efforts were enhanced by their honesty, guidance, support, and belief in the importance of this project.

We appreciate the leadership and support of the U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR). The guidance of Carol Cohen, Contract Officer of this study, has been invaluable to the success of this project.

Our gratitude is expressed to the many individuals and organizations who generously participated; the information they provided formed the basis of the findings and recommendations of this study. Special thanks are extended to the staff of Foundation for Technology Access for giving of their time to ensure that this study was represented by consumers of technology-related information.

We are indebted to our colleagues at the Center for Developmental Disabilities for their time, guidance, and support of this effort. Recognition is given to the staff of the Division of Information Technology for their review of the materials and assistance in identifying organizations for participation in the study. Specifically, we are grateful for their willingness to adjust priorities to help with this study. Special thanks are extended to Kathy Mayfield-Smith for her assistance with the literature review for this report.

Finally, we wish to express our thanks to the research staff of this study for their insight, persistence, and patience. They have logged countless hours to ensure that this study is responsive to the technology-related information needs of consumers. They can be proud of a job well done.

Ana Lopez- De Fede Project Director



t must be remembered that there is nothing more difficult to plan, more doubtful of success, more dangerous to manage than the creation of a new system. For the initiator has the enmity of all who would profit by the preservation of the old institutions and merely lukewarm defenders in those who would gain by the new ones.

Machiavelli (The Prince)

Executive Summary

evolutionary changes in technology our lives. Activities once perceived as complex and restrictive, such as the use of computers, have become part of everyday life. The application of technological advances provides the mechanisms for assisting individuals with disabilities to engage in an expanded range of activities. Assistive technology (AT) can provide the tools that allow individuals with disabilities to participate more fully in daily activities, gain more control over their own lives, and be provided with more access to pursue opportunities heretofore inaccessible. Information on assistive technology can determine what impact this technology has on the quality of life of individuals with disabilities. This study explored the feasibility of establishing a national assistive technology information and program referral (I&R) network from two differing perspectives:

- the current processes used to disseminate information about assistive technology, and
- the needs of individuals who want access to assistive technology information.

It investigated the essential mechanisms to link information on assistive technology with the individuals who need it. The study's major conclusion was that it is feasible and desirable to establish a national assistive technology information and program referral network.

METHODOLOGIES

The approach used divided the research into five components for this study:

PHASE I:

Expert Panel Group: A group of 16 individuals from the field of ATI&R provided input into the overall design of the research, reviewed the findings, and contributed to the final recommendations of the study.

PHASE II:

<u>Key Informant Survey</u>: A total of 541 AT I&R providers assessed the current state-of-practice in the field through a survey. Additionally, this survey tool addressed the feasibility and desirability of establishing a national assistive technology information and program referral network.

PHASE III:

<u>Consumer Needs Perspective</u>: Nationally, a total of 4,298 individuals determined the AT I&R needs of individuals with disabilities through a survey. Approximately 100 persons with disabilities of under-represented groups not found in the survey population provided their perspective via individual and group interviews.

PHASE IV:

Regional Focus Groups: Four focus groups examined the preliminary findings of the study developed in phases 1 through 3. These groups sought to clarify the initial findings and provided input on final recommendations. A total of 62 individuals participated in the focus groups.

PHASE V:

<u>Technical Barriers</u>: The researchers examined the technical barriers that might impede the establishment of a national AT I&R network.



STUDY PRODUCTS

- A comprehensive Final Report that integrates all phases of the research conducted in this study;
- An Executive Summary of the Final Report;
- A detailed Feasibility Report that explores impediments to development of a National ATI&R Network;
- A Consumer Perspective Report that examines the technology-related information needs of consumers;
- A Directory of AT I&R Providers; and
- An Annotated Bibliography of AT I&R Related Publications.

Copies in alternative formats of all reports are available upon request from the Center for Developmental Disabilities at the University of South Carolina.

SUME ARY OF KEY FINDINGS

This report is an executive summary which provides the study findings. Readers should examine the other reports for a more complete understanding of the issues affecting the Feasibility and Desirability of Establishing a National Assistive Technology Information and Program Referral Network.

The key issues identified concerning the establishment of a National Assistive Technology Information and Program Referral Network were similar across geographic areas, segments of the population, and service needs. The study documented the following technical factors as affecting the assistive technology information and program referral process:

- 1. Assistive technology information and program referral services are not uniformly defined:
 - Services differ from program to program;
 - Lack of coordination of information and referral services across community, state, regional, and national levels;
 - Population and geographic area served differ from program to program;
 - Access to the service differs and may not be reflective of the target service population or their accessibility needs; and
 - The term "assistive technology" may differ among service provider(s) and the target population who can benefit from the service.
- 2. Organizational structure of assistive technology information and program referral services are not uniform from program to program:
 - There is a lack of guidelines for staff patterns and requirements for AT I&R staff;
 - There is a lack of standards to guide the confidentiality of consumer information obtained by agencies in the provision of information services;
 - There is no apparent correlation between budget allocation and services and/or quality of service; and
 - Responsibilities of AT I&R staff differ from program to program.



3. Training for assistive technology information and program referral staff is flawed by the lack of standards and/or requirements for AT I&R staff:

- Assistive technology information and program referral staff are not traditionally trained to deliver AT I&R services but, rather, to respond to the limited information requests of a particular database or written publication;
- The whole-person concept is often not employed or not existent, with the emphasis placed on responding only to a specific request for a device; and
- There is a heavy reliance on written materials and time-dated databases where the information may or may not be accurate.

4. Information management is flawed by the lack of consistent methods to maintain, verify, and update information:

- Lack of funding and training on evaluation methodology seriously impedes the quality of information and service;
- Lack of training to guide the management of information may have a negative impact on the quality of information and its usability by consumers;
- Lack of compatible hardware and software can impede the ability to transfer and share data from program to program;
- Lack of a standard taxonomy and definition of terms can result in inconsistent information disseminated to consumers; and
- Lack of standards for data collection, data verification, and updates can impede the quality of information.

5. Outreach efforts to target populations are ineffective and/or non-existent:

- Formal evaluation of the target population is sporadic or lacking in quantifiable measures of effectiveness:
- The lack of available information on quality indicator measures, e.g.., "consumer report" type rating for assistive technology devices;
- Lack of information on problem-solving strategies that allow consumers to maneuver through a complex system of care;
- Underserved populations are not targeted or not reached due to a heavy reliance on traditional publicity and outreach methods;
- Outreach efforts are primarily in written format, thereby limiting the target population; and
- The lack of formal evaluation can result in services that do not meet the needs of the target audience.



RECOMMENDATIONS

In response to the major findings of the study, the following recommendations are made to NIDRR. The recommendations are grouped into five major areas: Policy; Coordination of AT I&R Services; Information Management; Staffing of AT I&R Services; Outreach; and Promoting AT I&R Services.

POLICY RECOMMENDATIONS

- 1. Establish a national AT I&R network to help coordinate and disseminate information on technology-related assistance for persons with disabilities.
- 2. Commit the necessary federal resources to implement strategies to improve the current state of AT I&R practices.
- 3. Commit the necessary resources to improve the delivery of AT I&R services at the federal, state, and local community levels.
- 4. Convene a national meeting of federal agencies to develop strategies designed to help coordinate and improve the delivery of I&R services.
- 5. Convene a National Assistive Technology Information and Program Referral Commission to develop strategies for improved coordination of technology-related services. This commission should include representatives from consumer groups, professional associations, public-sector agencies, private non-profit agencies, private for-profit companies, and I&R practitioners.
- 6. Establish a national AT I&R toll-free telephone number to link persons with disabilities and AT services providers with appropriate resources. This service must be accessible in a variety of formats and provide linkages to referral at the local and state levels.
- 7. Establish a national assistive technology evaluation project to provide indicators to help consumers determine the quality and applicability of services and devices in meeting their technology needs.
- 8. Conduct field initiated research of I&R "best practices" and their application in the dissemination of AT information.
- 9. Develop a national classification "taxonomy" for the delivery of AT I&R services.
- 10. Conduct a national awareness campaign on assistive technology with parallel emphasis on I&R activities at the regional, state, and lwocal levels. The target population of this campaign will be consumers of technology-related services, with emphasis on reaching both formal and informal resources utilized by persons with disabilities.
- 11. Develop a national resource and technical support coordinating institute to:
 - Facilitate a coordinate approach for the delivery of AT I&R services.
 - Provide technical support to AT I&R services.
 - Develop national training materials to enhance the delivery of AT I&R services.
 - Provide training to enhance the capacity of I&R staff to deliver AT I&R services.



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COORDINATION OF AT 1&R SERVICES RECOMMENDATIONS

- 1. Implement coordination strategies that build upon cooperative agreements between federal agencies providing I&R services, institute standards of performance for the provision of AT services, and other mechanisms to enhance coordination of technology-related information for persons with disabilities and their families.
- 2. Develop a technical assistance manual for the coordination of AT I&R services, which details strategies within the context of the options available to deliver I&R services.
- 3. Provide leadership to develop a National Assistive Technology Information and Program Referral Coordinating Institute. NIDRR will provide the oversight for the activities of the Coordinating Institute.
- 4. Develop and implement a plan for a fully-coordinated ATI&R delivery system, with centralized functions providing technical support needed by community ATI&R services.
- 5. Develop and implement initiatives that recognize the value of I&R services and build support for a coordinated system.

INFORMATION MANAGEMENT RECOMMENDATIONS

- 1. Establish a mechanism to review, modify, or adapt the "Standards for Information and Referral" and the "Taxonomy of Human Services", developed by the Alliance for Information and Referral Systems, for use by NIDRR-funded AT I&R services. If adaptation is not feasible, develop standards and an assistive technology services taxonomy.
- 2. Provide the technical and training support for projects to implement minimum standards on information management and a taxonomy for the delivery of AT I&R services.
- 3. Establish annual priorities for field initiated research on the "best practices" in the delivery of AT I&R services.
- Establish a mechanism to examine hardware and software options for all NIDRR-funded AT I&R services and determine their suitability, strengths, and weaknesses.
- 5. Develop guidelines and options for the selection of computer hardware and software to maximize compatibility among ATI&R services. The lack of compatibility can severely restrict the ability to electronically link ATI&R services.
- 6. Provide technical support to AT I&R services in the selection and utilization of computer hardware and software.
- 7. Develop consumer-responsive guidelines and evaluation strategies to measure the effectiveness of AT I&R services.



STAFFING AT I&R SERVICES RECOMMENDATIONS

- 1. Establish mechanisms to develop minimum competency guidelines for AT I&R staff.
- 2. Develop mechanisms to provide technical and training support for AT I&R services and I&R staff to implement the following:
 - Implementing standards;
 - Utilizing an AT I&R Services Taxonomy;
 - Meeting minimum competency levels; and
 - Developing in-depth expertise in various health and human service programs and technology-related issues.
- 3. Develop mechanisms for sharing training materials, innovative approaches, strategies, and technological applications.

OUTREACH RECOMMENDATIONS

- 1. Establish mechanisms to develop and implement minimum standards of evaluation on the effectiveness of AT I&R services.
- Develop outreach partnerships with corporations, public and private organizations, broadcast media, civic associations, and other groups to launch a national awareness campaign on assistive technology.
- 3. Establish demonstration projects to test innovative approaches to underserved and underrepresented groups by AT I&R services.
- 4. Establish a mechanism to provide technical support and training on outreach strategies with formal and information brokers.
- 5. Provide the technical support and resources to AT I&R services for developing outreach strategies with underserved and under-represented groups.

PROMOTING AT I&R SERVICES RECOMMENDATIONS

- 1. Initiate local community promotional campaigns that parallel a national assistive technology awareness campaign. Local community promotional campaigns can include public service announcements, video productions, and printed media.
- 2. Establish statewide 1-800 AT I&R telephone numbers. The state numbers are an essential link between the national 1-800 system and local communities.

A concise list of the recommendations to build a National Agenda to Improve ATI&R Services follows.



LIST OF RECOMMENDATIONS

A NATIONAL AGENDA FOR IMPROVING AT I&R SERVICES

POLICY RECOMMENDATIONS

Establish a national AT I&R network

Commit federal resources to implement strategies to improve the state of AT I&R practice

Commit resources to improve the delivery of AT I&R services

Convene a national meeting of federal agencies

Convene a National Assistive Technology Information and Program Referral Commission

Establish a national AT I&R toll-free telephone number

Establish a national assistive technology evaluation project

Conduct field initiated research of I&R "best practices"

Develop a national classification "taxonomy" for the delivery of AT I&R services

Conduct a national awareness campaign on assistive technology

Develop a national resource and technical support coordinating institute

COORDINATION OF AT I&R SERVICES RECOMMENDATIONS

implement coordination strategies between federal agencies providing I&R services

Develop a technical assistance manual for the coordination of AT I&R services

Provide leadership to develop a National Assistive Technology Information and Program Referral Coordinating Institute

Develop and implement a plan for a coordinated AT I&R delivery system

Develop and implement initiatives that recognize the value of I&R services

INFORMATION MANAGEMENT RECOMMENDATIONS

Establish a mechanism to develop standards and an assistive technology services taxonomy Provide the technical and training support to implement minimum standards on information

management

Establish annual priorities for field initiated research on the "best AT I&R practices"

Examine hardware and software options for all NIDRR-funded AT I&R services

Develop guidelines and options for the selection of computer hardware and software

Provide technical support to AT I&R services

Develop consumer-responsive guidelines and evaluation strategies

STAFFING AT IAR SERVICES RECOMMENDATIONS

Develop competency guidelines for AT I&R staff

Develop mechanisms to provide technical and training support for AT I&R services and I&R staff

Develop mechanisms for sharing training materials, innovative approaches, strategies, and technical applications

OUTREACH RECOMMENDATIONS

Develop and implement minimum standards of evaluation

Develop outreach partnerships

Establish demonstration projects serving underserved and under-represented groups by AT I&R

Provide technical support and training on outreach strategies with formal and Information brokers

Provide the technical support and resources to AT i&R services

PROMOTING AT I&R SERVICES RECOMMENDATIONS

initiate local community promotional campaigns

Establish statewide 1-800 AT I&R telephone numbers



Chapter One

INTRODUCTION

evolutionary changes in technology affect all of us. Activities once perceived as complex and restrictive, such as the use of computers, have become part of everyday life. The application of technological advances provides the mechanisms for assisting individuals with disabilities to engage in an expanded range of activities. Assistive technology (AT) can provide the tools that allow individuals with disabilities to participate more fully in daily activities, gain more control over their own lives, and be provided with more access to pursue opportunities heretofore inaccessible.

The problem for most individuals with disabilities and their families is knowing where to turn for information on AT services and devices. The response to this quandary has been to develop mechanisms for the delivery of information and program referral (I&R). I&R is a process to provide information by identifying organizations and individuals who can render the appropriate service(s). I&R can be provided informally through human service providers or formally through I&R services. The foci of these services will vary according to five factors (i.e., geographic areas covered, populations served, funding source[s], I&R staffing patterns, and management of information databases). However, consumers of AT I&R services may need comprehensive information to merge technology needs with their medical and psycho-social requirements. A generic I&R service or a specialized assistive device I&R service may not be able to meet all of their information needs. In an environment of many I&R services and consumer informational needs it is difficult to determine the best approach to delivery of AT I&R services.

The Technology-Related Assistance for Individuals with Disabilities ACT of 1988 called for a study "to determine the feasibility of creating a national information and program referral network." This report details the results of the study funded by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR).

PURPOSE AND OBJECTIVES OF THE STUDY

The Center for Developmental Disabilities of the University of South Carolina (CDD) conducted this study to determine the feasibility and desirability of creating a national AT I&R network. The primary goals of the study were:

- To determine the feasibility and desirability of establishing an national AT I&R network;
- To ascertain the technology-related information needs of consumers, policy makers, planners, and other professionals;
- To assess the current practices and status of technology-related I&R services; and
- To recommend strategies for developing technology-related I&R services that meet the needs of persons with disabilities and their families.



The research approach employed to meet these goals divided the research into five components for study:

PHASE I:

Expert Panel Group: A group of 16 individuals from the field of assistive technology I&R provided input into the overall design of the research, reviewed the findings, and contributed to the final recommendations of the study.

PHASE II:

Key Informant Survey: A total of 541 ATI&R providers assessed the current state of practice in the field through a survey. Additionally, this survey tool addressed the feasibility and desirability of establishing a national assistive technology information and program referral network.

PHASE III:

<u>Consumer Needs Perspective</u>: Nationally, a total of 4,298 individuals determined the AT I&R needs of individuals with disabilities through a survey. Approximately 100 persons with disabilities of under-represented groups not found in the survey population provided their perspective via individual and group interviews.

PHASE IV:

<u>Regional Focus Groups</u>: Four focus groups examined the preliminary findings of the study developed in phases 1 through 3. These groups sought to clarify the initial findings and provided input on final recommendations. A total of 62 individuals participated in the focus groups.

PHASE V:

<u>Technical Barriers</u>: The researchers examined the technical barriers that might impede the establishment of a national AT I&R network.

This report presents the activities, findings, and conclusions of each phase of the study. Recommendations are provided with a proposed plan to meet the assistive technology-related needs of persons with disabilities, service providers, agencies, and individual professionals. The approach utilized for this study is illustrated in Figure 1.

STUDY ORGANIZATION AND RESPONSIBILITIES

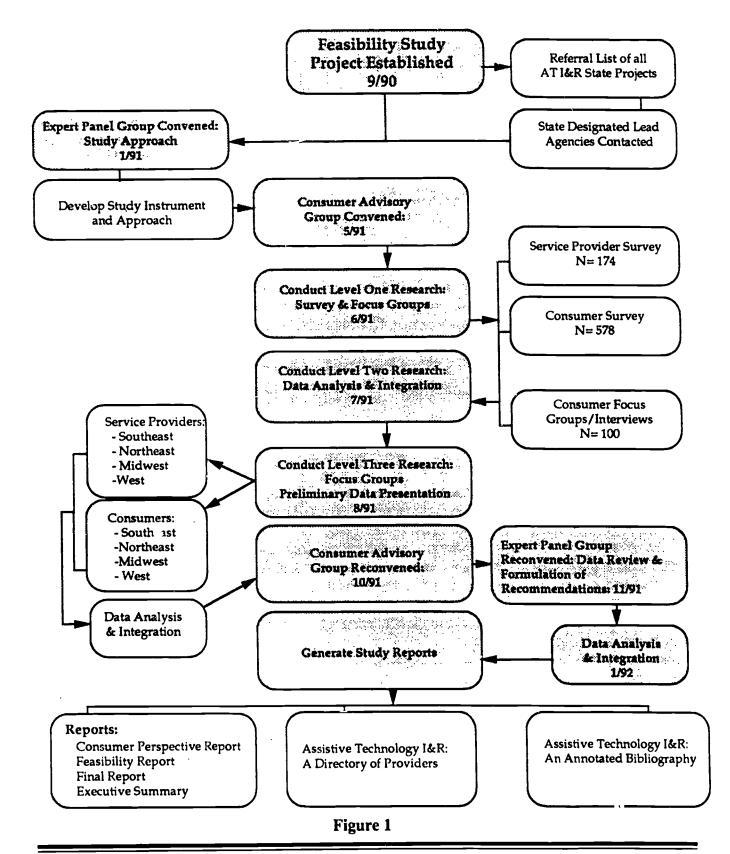
The CDD served as the principal contractor for this study. The contractor employed a collaborative approach toward meeting study goals. As such, four organizations served as sub-contractors, performing the following activities:

This report presents the activities, findings, and conclusions of each phase of the study. Recommendations are provided with a proposed plan to meet the assistive technology-related needs of persons with disabilities, service providers, agencies, and individual professionals.

• RESNA, Inc., took principal responsibility for providing a consumer oversight on all aspects of the study. This included converting the survey instrument into alternative formats, convening and facilitating a Consumers' Advisory Group, conducting regional focus groups, and conducting individual interviews with under-represented populations. The staff of CDD and RESNA shared responsibility for the content of the study tools, post-field-work data processing, and the consumer perspective final report.



Assistive Technology I&R Feasibility Study Flowchart of Research Approach





- The Center for Persons With Disabilities of the University of Utah organized, coordinated, and facilitated a regional focus group of midwestern states. The staff served as independent reviewers of study instruments and preliminary findings for the development of study recommendations.
- The World Institute for Disabilities, Inc., organized, coordinated, and facilitated a regional focus group of western states.
- The Trace Research and Development Center of the University of Wisconsin at Madison provided technical assistance and consultation on the use of computer technology in the delivery of AT I&R services. The staff served as independent reviewers of study instruments and preliminary findings for the development of study recommendations.

STUDY BOUNDARIES AND LIMITATIONS

The approach used to study the feasibility and desirability of establishing a national AT I&R network was restricted by four factors:

- The broad definitions used to define the terms "assistive technology" and "network";
- Access to a representative national sample population of potential users of AT I&R services;
- The voluntary nature of the study, which allowed NIDRR-funded projects with ATI&R activities to choose the level of participation; and
- The time period during which State-funded assistive technology programs had been providing AT I&R services.

Definitions

The Technology-Related Assistance For Individuals With Disabilities Act of 1988 broadly defines assistive technology services and devices. The act defines assistive devices as "any item, piece of equipment, or product system used to increase, maintain, or improve the functional capabilities of individuals with disabilities." Assistive technology services are defined as any activity that "directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device." This study examined information and program referral services within the context of these two very broad definitions. In designing this study the staff utilized the broad definition of assistive technology; however, it limited the scope of information and program referral services to established information providers within the United States.

The word "network" was found to have differing meanings within the service provider and consumer communities. As a result, the survey responses were inclined toward the individual definition ascribed by the respondent to the word "network". The combination of research methodologies used throughout this study (see Figure 1) allowed for clarification and development of a working definition to be used in the creation of a national assistive technology information and program referral network.

Sample Population

The target population for this phase was consumers of assistive technology-related information. A random national sample of this population cannot be obtained because the total population of persons with disabilities who meet the study criteria is not known and no standard definition exists to define assistive



technology information and program referral services. As a result, the study methodology sought to address these factors through the inclusion of a broad national representation of persons with disabilities. A detailed discussion of the sample population of this study is found in Chapter Three.

The study sought to involve a wide constituency of individuals with disabilities. This approach minimized the inherent difficulties in conducting this type of research, i.e., the researchers utilized a comprehensive approach for identifying potential participants in the study. The value of this approach was that it also allowed data to be gathered on participants who could not be reached through the use of standard survey tools. Thus, the quantitative survey data was enriched through the use of qualitative methods, i.e., focus groups and individual interviews. The lack of research specific to AT information and program referral services prompted the researchers to employ this approach. Future studies can benefit from this work to define research parameters in quantitative measures.

Participation of AT I&R Providers

Voluntary participation is an essential criteria in conducting meaningful research. However, it can severely limit the information available to researchers for analysis. As an example, information on activities involving the development of an electronic network through SERIES, the State-funded Assistive Technology Projects under the auspices of the State Departments of Vocational Rehabilitation, and major clearinghouses provided partial or no information on organizational structure, funding levels, staffing patterns, services, or populations served through AT I&R activities. The researchers made several attempts to include these programs as part of the study sample. Each program was contacted on six separate occasions via mail and telephone to encourage participation. Twenty programs under this category chose not to participate. Thus, the findings may be restricted to the study sample and not a more global population with similar characteristics. The lack of information on these programs may affect the ability of researchers to project funding and staffing patterns for future activities.

Assistive Technology State-Funded Projects

This phase of the study was prepared during a time period when many of the State-funded projects were just beginning to establish AT I&R services. As a result, some of the projects could not complete the survey instrument or provide information on their AT I&R activities. In order to solicit their input, an invitation was extended to participate in the regional focus groups (see Appendix A: Regional Focus Group Participants and Focus Group Moderator's Guide). These focus groups created a forum for reviewing the preliminary findings of the study and soliciting recommendations for policy changes.

STUDY PRODUCTS

The results of the Study have been presented in several other reports, including:

- a detailed Feasibility Report that explores impediments to development of a National AT I&R Network;
- an Executive Summary of the Final Report;
- a Consumer Perspective Report that examines the technology-related information needs of consumers;
- a Directory of AT I&R Providers; and
- an Annotated Bibliography of AT I&R Related Publications.



in conducting the study, two survey instruments were developed for use in assessing the AT information needs of persons with disabilities and the state-of-the-practice of AT I&R services (see Appendix B). The two survey instruments are listed below:

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- Consumer Survey: Assistive Technology Information and Referral Services for Persons with Disabilities;
- ATI&R Provider Survey: Practices in the Assistive Technology Information and Referral field.

Alternative formats of the products are available upon request from the Center for Developmental Disabilities at the University of South Carolina.

SUMMARY OF KEY FINDINGS

This summary provides an overview of the results of the Study on the Feasibility of Establishing a National Assistive Technology Information and Program Referral Network.

The key issues identified concerning the establishment of a National Assistive Technology Information and Program Referral Network were similar across geographic areas, segments of the population, and service needs. The study documented the following technical factors as affecting the assistive technology information and program referral process:

- 1. Assistive technology information and program referral services are not uniformly defined:
- Services differ from program to program;
- Population and geographic area served differ from program to program;
- Access to the service differs and may not be reflective of the target service population or their accessibility needs; and
- The term "assistive technology" may differ among service provider(s) and the target population who can benefit from the service.
- 2. Organizational structure of assistive technology information and program referral services are not uniform from program to program:
- There is a lack of guidelines for staff patterns and requirements for AT I&R staff;
- There is no apparent correlation between budget allocation and services and/or quality of service; and
- Responsibilities of AT I&R staff differ from program to program.



- 3. Training for assistive technology information and program referral staff is flawed by the lack of standards and/or requirements for AT I&R staff:
- Assistive technology information and program referral staff are not traditionally trained to deliver AT I&R services but, rather, to respond to the limited information requests of a particular database or written publication;
- The whole-person concept is often not employed or not existent, with the emphasis placed on responding only to a specific request for a device; and
- There is a heavy reliance on written materials and time-dated databases where the information may or may not be accurate.
- 4. Information management is flawed by the lack of consistent methods to maintain, verify, and update information:
- Lack of funding and training on evaluation methodology seriously impedes the quality of information and service;
- Lack of training to guide the management of information may have a negative impact on the quality of information and its usability by consumers;
- Lack of compatible hardware and software can impede the ability to transfer and share data from program to program;
- Lack of a standard taxonomy and definition of terms can result in inconsistent information disseminated to consumers; and
- Lack of standards for data collection, data verification, and updates can impede the quality of information.
- 5. Outreach efforts to target populations are ineffective and/or non-existent:
- Formal evaluation of the target population is sporadic or lacking in quantifiable measures of effectiveness:
- Underserved populations are not targeted or not reached due to a heavy reliance on traditional publicity and outreach methods;
- Outreach efforts are primarily in written format, thereby limiting the target population; and
- The lack of formal evaluation can result in services that do not meet the needs of the target audience.

The study documented the following needs of consumers relative to AT Information and Program Referral Services. Consumers desire:

- 1. Comprehensive information and program referral services;
- 2. Increased public awareness on both the value and application of assistive technology to meet needs of persons with disabilities;
- 3. Information and program referral service staff that are trained, sensitive, and knowledgeable;



- 4. Standards to guide the confidentiality of consumer information obtained by agencies in the provision of information services;
- 5. Information measures that assure quality, accuracy, and timeliness of information provided;
- 6. Clear and consistent definitions for assistive technology services and devices used by service providers and information providers;
- 7. Available information on quality indicator measures, e.g., "consumer report" type ratings, for assistive technology devices;
- 8. Coordination of information and referral services across community, state, regional, and national levels:
- 9. Established standards that measure the effectiveness of information and program referral services to meet the needs of the targeted population; and
- 10. Information on problem-solving strategies that allow consumers to maneuver through a complex system of care.

The findings suggest that a critical review is needed of the current state of AT I&R services. Subsequent chapters examine these findings and their relationship to the feasibility of establishing a National Assistive Technology Information and Program Referral Network.



Chapter Two

LITERATURE REVIEW

ccess to information has been described as the "lifeline" between individuals and the service delivery community. Accessibility is an essential requirement if individuals are to meet their needs in a complex system of care. Levinson (1984) refers to this complex system of care as planless, resulting in a society that is "overserviced and underserved". As a result, individuals must often go from one agency to another in an attempt to find help. For individuals in need of help, this "ping-pong" process leads to frustration and disillusionment with their ability to receive answers to their questions. The Overview report of the President's Reorganization Project summarized the status of the current system of care:

It would be difficult to design, or even imagine, a more confusing, inefficient, costly, and less productive enterprise than the existing human services delivery system. There are more than 140,000 community-based organizations, 28,000 local governments, and 50 different State governmental configurations. These agencies are funded, guided, regulated, visited, assessed, assisted, reviewed, monitored, evaluated, and audited by more than 100 Federal programs in 10 Federal agencies (Levinson, 1981).

How does an individual gain access to information on a needed service within this complex system of care?

In response to this dilemma, the information and program referral (I&R) process was born to link individuals with needed services. The beginnings of I&R services can be traced to the Social Services Exchanges operated in the late nineteenth century. The early purpose of these services was "to facilitate communication among agencies in order to enhance service coordination." The focus of these early attempts was to help the professionals providing these services and not individual accessibility to them (Morris, 1987).

In the 1920s, the United Community Councils of America (currently known as the United Way of America) began the first organized I&R programs at the community level. The role of these councils was two-fold:

- 1. To develop plans and funding to meet the human services needs of the community, and
- 2. To publish a directory of community agencies (Levinson, 1981).

The role of I&R programs remained exclusively at the community level until the 1960s. The passage of the Older Americans Act of 1965 and the Older Americans Act Amendments of 1973 launched a new era of I&R programs. These acts required all Area on Aging offices to have available I&R services for older persons. The goal was to facilitate access to the services needed by older Americans. As a result, in 1978 the Administration on Aging developed working agreements with other federal departments and agencies to develop cooperation in establishing information and referral initiatives. These agreements were to serve as the basis for the development of a network on aging to promote collaborative efforts in the development of I&R services. A further step was taken with the social service legislation under Title XX (Social Security Act), which provided funds for program development and training. This legislation recognized the need for the "universal provision of I&R services," mandating their availability to everyone, regardless of income, age, and residence (Levinson, 1981).



The federal legislation and provision spearheaded by the Administration on Aging and the United Way gave life to the development of I&R services. However, it has been the rapid growth of technology and the disability movement that has resulted in specialized I&R services for persons with disabilities. These services have promoted the need to develop I&R services that can meet the needs of individuals with disabilities. Ziegler (1989) cites seven key areas of information to be provided through an I&R service to meet the information needs of parents with a special needs child. The areas of information he suggests are:

- 1. Information about the disability itself not only limitations but also possibilities, treatment choices, preferred methods, and success stories.
- 2. Knowledge of relevant laws.
- 3. Knowledge about services available to the child and family.
- 4. Exposure to "state-of-the-art" programs.
- 5. Understanding of the importance of and implications for various tests or assessments.
- 6. Information about sources of financial assistance.
- 7. Knowledge about the community in which the family lives, as well as relevant agencies outside of their immediate geographic area.

In an attempt to meet the information needs of individuals with disabilities, specific provisions for I&R services have been included in every major disability-related legislation during the past decade. A summary list of federal disability legislation related to information and program referral initiatives is found on page 19.

A publication reviewing I&R-related publications was developed as part of this study. This publication, An Annotated Bibliography of Assistive Technology-Related Publications, provides a summary of some of the resources available to I&R practitioners.

CURRENT STATE OF I&R PRACTICE

I&R services present a doorway to existing resources by providing an organized method by which to connect individuals with needed services. However, not all I&R services are provided in a similar or consistent manner. According to the U.S. General Accounting Office report on Information and Referral in 1978, the I&R field "had become part of the maze to which they were supposed to offer guidance." The report cites that the unplanned growth and coordination of I&R services have resulted in a "fragmented system characterized by duplication of and competition between services and functions; waste of resources; barriers obstructing access; and inadequate services" (GAO, 1978). To overcome these barriers, the following were needed:

- Standardized reporting mechanisms;
- A uniform classification system; and
- Quality assurance standards for information management.

The Federal Interdepartmental Task Force to promote collaborative efforts in I&R development cited that "information and referral services were uneven in quality and accessibility" (Referral Services Report, 1983). The lack of consistent funding and importance related to other human service activities were cited as factors that hindered overcoming the identified barriers.



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Federal Disability Legislation Related to Information and Referral

- Older Americans Act of 1965 and Amendments of 1973 required all area agencies on aging to have available I&R services for older persons.
- Social Security Act, Title XX recognized the need for the "universal provision of I&R services."
- The Developmental Disabilities Assistance and Bill of Rights Act (1975, Amendments 1987) gave authority to the Protection and Advocacy Systems in every state to "provide information and referral to programs and services addressing the needs of persons with developmental disabilities."
- Education for All Handicapped Persons Act (PL 94-142, 1975) established a National Information Center for Handicapped Children and Youth to provide information about special education-related issues for parents.
- Child Abuse Prevention and Treatment Act (PL 98-457, 1986; PL 100-294
 Amendments of 1988) mandated the establishment of a National Clearinghouse for
 Infants with Disabilities and Life-Threatening Conditions and their families.
- Education of the Handicapped Act (PL 99-457, Title 1, Part H) required as part of each state's coordinated system of care for infants and toddlers "a Central Directory which includes early intervention services, resources, and experts available in the state."
- Title V Maternal and Child Health Services Block Grant required that the state's
 administering agency provide a toll-free telephone number for the use of parents to
 access information about health care providers and practitioners who provide health
 care services under this title and Title XIX and about other relevant health-related
 providers and practitioners.
- Technology-Related Assistance Act (PL 100-407, § 101) required that states disseminate information on assistive technology services and devices.



The findings of the GAO study (1978) are an accurate reflection of the current state of I&R practices. A diversity of I&R systems exists today, operating under different organizational auspices, such as libraries and human service agencies. Some are designated to serve all individuals and age groups, while others serve a designated target population. Funding sources often play a key role in determining staffing patterns and whether the system is centralized or decentralized. The Nationwide Information and Referral for Persons with Developmental Disabilities Study 1990) concludes the following on the national current state of practice:

- Seventy-one percent of I&R providers offer services at the local community level;
- The more specialized the I&R agency, the more likely it is to serve a large area;
- Eighty-one percent of I&R services are designed to be used by anyone needing information; and
- Fifty-eight percent of the respondents have multiple funding sources.

The challenge of providing accurate, timely, and quality I&R services is still ahead of us as a society. New challenges and opportunities face the I&R field with the onset of information technology. The advent of technological advances in the communication field through worldwide networks, teleconferencing, multimedia, and computer and software strides will make managing information an easier task. This is a time period when it is possible to merge the needs of our service delivery system with the innovations of the communication field. Caution must be exercised as these two areas merge not to lose sight of the essential building blocks that provide access to information. The most technically-advanced I&R system is useless if it does not meet the information needs of individuals accessing the service (Mayfield-Smith, 1990).



Chapter Three

SUBSTANTIVE RESULTS OF THE FEASIBILITY AND DESIRABILITY STUDY

hat services exist for the myriad of consumers of technology-related information in our society? In the past, the information needs of consumers were often met with confusion by information providers who lacked information about assistive technology services and devices. The Technology-Related Assistance for Individuals with Disabilities Act of 1988 revolutionized consumers' ability to access assistive technology information. Much of the credit for these changes goes to NIDRR-funded information dissemination programs. Still, the material available to date from the nation's AT I&R services consists primarily of listings of programs' names and addresses and brief descriptions of services. This study gives the first national perspective on AT I&R services and the consumers of these services. It examines trends, patterns of program development, consumer needs, and the current state of practice.

The needs assessment of this study documented that it is feasible and desirable to establish a national AT I&R network. The network must allow I&R services to be autonomous from one another and yet provide a coordinated approach for the delivery of AT I&R services. This study corroborated that it is possible to link together existing AT I&R systems through a network only when or if the network provides supportive services for its members. These supportive services must enhance the ability of AT I&R services to provide quality, timely, and accurate information.

The completed surveys of 578 consumer respondents, 174 AT I&R providers, and 200 key informants provided the data for this chapter.

PROFILE OF THE AT I&R PROVIDER STUDY RESPONDENTS

The study examined whether AT I&R services classify their activities as the central focus and responsibility of the agency, a formally designated service of the agency, or a service provided upon request by consumers. Most AT I&R providers (101, or 59%) classified their services as formally designated services of their agencies or the central focus and responsibility of the agencies. Generally, respondents in this group reported a greater diversity of stable funding and reliance on paid I&R staff. In contrast, many I&R services providing AT information upon request relied on volunteer I&R staff and unstable funding for support.

The respondents were from all parts of the United States and represented a wide geographic distribution. There were respondents from 52 states and territories, representing all 10 Health and Human Services regions of the United States. Those states with the largest number of responding AT I&R services were Maryland (10), Massachusetts (8), Texas (8), Indiana (7), California (7), Arkansas (6), and Wisconsin (6) (see Table 1).

Ninety-five percent of the participants rated their AT I&R services as essential relative to other services provided by the agency. All respondents provided some type of technology-related information and program referral service. They represented a cross-section of AT I&R providers in urban, suburban, and rural areas in all parts of the United States.

The development of AT I&R services is a recent phenomenon. Whereas rehabilitation-related services have been available for more than a century, formalized AT I&R services have existed since the 1980s. The study



TABLE 1

REGIONAL REPRESENTATION OF AT I&R SERVICES SURVEYED*

N = 173 Respondents

N = 173 Respondents			
REGION	NO. OF PROGRAMS	REGION	NO. OF PROGRAMS
Region I Connecticut Maine Massachusetts New Hampshire Rhode Island Vermont Virgin Islands TOTAL	4 3 8 1 1 2 1 20	Region VI Arkansas Louisiana New Mexico Oklahoma Texas TOTAL	6 3 1 3 8 21
Region II New Jersey New York TOTAL	2 4 6	Region VII Iowa Kansas Missouri Nebraska TOTAL	3 5 1 3 12
Region III Delaware District of Columbia Maryland Pennsylvania Virginia West Virginia TOTAL	1 6 10 3 4 3 27	Region VIII Colorado Montana North Dakota South Dakota Utah Wyoming TOTAL	1 1 1 2 3 3 11
Region IV Alabama Florida Georgia Kentucky Mississippi North Carolina South Carolina Tennessee TOTAL	1 5 4 3 2 5 3 3 3 26	Region IX Arizona California Hawaii Nevada TOTAL	4 7 1 2 14
Region V Illinois Indiana Michigan Minnesota Ohio Wisconsin TOTAL	3 7 5 5 2 6 28	Region X Alaska Idaho Oregon Washington TOTAL	1 2 1 4 8

Figures derived from respondents represented in Assistive Technology Information and Program Referral: A Directory of Providers.



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data documented that more than 80% of the AT I&R services were developed between 1980 and 1991. The respondents surveyed reported having been in operation an average of six years. At the time of the survey, Assistive Technology State-funded projects reported an operating range between two months and three years. These findings illustrate the phenomenal growth of AT I&R services after 1980 and the lack of homogeneity among existing services.

A listing of 541 AT I&R providers was developed by cross-indexing 3 lists of programs: a listing of NIDRR-funded projects, obtained from the U.S. Department of Education; the membership directory of the Alliance of Information and Referral Systems; and the Rehabilitation Technology Services Delivery Directory developed by RESNA, Inc. In February, 1991, a detailed 13-page questionnaire was developed, pretested, revised, and mailed with a cover letter to 541 providers. By May, 1991, 174 complete questionnaires constituted the survey study sample, a 32.2% response rate. Of the 174 providers, the auspices of the responding programs varied from advocacy programs to State-funded assistive technology programs (see Table 2).

Table 2
Response Rate of Asssitive Technology I&R Provider Survey
N = 174

Auspices	Percent of Respondents
Advocacy Consumer Organizations	29.73%
Bulletin Board Network	29.41%
Federal Agencies	20.00%
Information Databases/Research	35.29%
National Information and Referral	30.28%
NIDDR Rehabilitation Engineering Centers	46.15%
Other Assistive Technology Organizations	35.00%
Professional and Trade Organizations	33.33%
Regional Resource Centers	36.00%
Resource Centers with National Focus	42.86%
Research Programs- Rehabilitation Technology	60.00%
Rehabilitation Technology Services	20.63%
Lead State Agencies	51.79%
Others Referred by State Agencies	33.33%
University Affiliated Programs	20.93%
NIDDR Technology Oriented Projects	31.82%
TOTAL	32.16%

A composite profile of the average AT I&&R provider survey participant follows.



Profile of the Average AT I&R Service Provider

- Classifies their AT I&R services as a "formal service" of the agency (86 or 49%).
- Rates AT I&R services as an "essential" service of their agency (123 or 71%).
- Concentrates on providing I&R services on "adaptive equipment." (130 or 75%).
- Serves all age groups and types of disabilities (138 or 79%).
- Primarily serves persons with disabilities or direct service providers (7,780 or 46%).
- I&R information is focused at the state level (99 or 44%).
- Services are accessed via a toll-free 1-800 telephone number (2,847 or 54%*).
- ATI&R staff is primarily composed of part-time and volunteer personnel.
- Annual AT I&R operating budge is \$25,000.
- More than 56% of budget is allocated to staff.
- Uses computerized information AT I&R database with an average of 4,000 listings (110 or 63%).
- Does not use a standard taxonomy for information management (110 or 43%).
- Uses a version of ABLEDATA to supplement their database (93 or 76%).
- Makes referrals outside of their operating area to national or regional I&R services (62%).
- Conducts follow-up services with consumers of their services via a telephone call within six months of the referral (90 or 52%).



Refers to number of calls. All other figures are numbers of respondents.

Individual profiles of the ATI&R providers who participated in this study can be found in the publication Assistive Technology Information and Program Referral: A Directory of Providers.

Information collected from 174 completed surveys and focus and nominal group meetings infers several key organizational areas common to all ATI&R services. These areas comprise the primary sections for analysis. They are as follows:

- Types of Services Available;
- Population Served;
- Consumer Access to AT I&R Services;
- Organizational Structure;
- Self-Reported Priority of Needed Changes to Existing Services;
- Self-Reported Priority of Factors Interfering With the Objectives and Operation of the Service;
- Outreach Efforts; and
- Feasibility and Desirability of Establishing a National Assistive Technology Information and Program Referral Network.

PROFILE OF THE AT I&R CONSUMER STUDY RESPONDENTS

The consumer study respondents were a nationally representative sample of persons with disabilities and their family members, parents, advocates, and friends. In March, 1991, a seven-page survey was mailed to 4,298 consumers. Five hundred forty-eight completed surveys of the 4,298 mailed constituted the survey sample, a 13% return rate. Of the total number of consumer survey respondents, 69% described themselves as persons with disabilities, 17% as parents of individuals with disabilities, and 10% as family members. One hundred key consumer respondents described themselves as either a person with a disability or as the parents of individuals with disabilities.

A composite profile of AT I&R consumer survey participants and their children showed the following:

- 1. Reported ages ranged from 6 months to 95 years of age.
- 2. Forty-six percent reported living with physical or multiple disabilities.
- 3. Place of residence: city (44%), rural area or farm (20%), town (20%), and small town (11%).
- 4. Sixty-two percent of the respondents expressed a need to find information on assistive technology-related services or devices during the preceding year.
- 5. Frequency of need for technology-related information was a result of the following:
- Perceived availability of funding;
- Respondents' knowledge about assistive technology;
- Respondents' ages; and
- Respondents' disabilities.



6. In the preceding year, 15% of the respondents paid a fee to use an information service.

The overwhelming majority of respondents (84.7%) associate their use of AT I&R services with their ability to access the service in multiple formats and the quality of the information provided by trained staff members.

Several key factors emerged as essential linkages between providers and consumers of technology-related information services. These linkages identified the areas for analysis and are as follows:

- Consumer desired type of technology-related information;
- Best access formats;
- Preferred outreach efforts;
- Knowledge of existing AT I&R resources;
- Preferred AT information based on the location of the AT I&R service;
- Resources consumers turn to for technology-related information; and
- Feasibility and desirability of establishing a National Assistive Technology Information and Program Referral Network.

Subsequent sections explore these factors in terms of all the phases examined throughout this study.

THE DESIRABILITY OF ESTABLISHING A NATIONAL AT I&R NETWORK

Consumers and technology-related information providers strongly desired and supported the establishment of a national AT I&R network. Sixty-nine percent of the consumer respondents affirmed that if a national AT I&R network was available they would use it to obtain information on assistive technology services and devices. Fifty-three percent of AT information providers stated that a national AT I&R network would benefit their callers and expand their ability to provide services. The following selected comments are from participants of the study who supported the desirability of establishing a national AT I&R network:

"This is a great idea! Most disabled people I know do not have much information about assistive products and devices."

North Carolina Resident (40-year-old person with a physical disability)

The National AT I&R Network must address the existing

AT IAR services.

"We provide very general I&R. It would be great to have somewhere to refer people with specific assistive technology needs rather than having to try all kinds of places before you find the right referral."

Information and Referral Provider (Help Central of Ames, Iowa [formerly Open Line, Inc.])

Thirty-three percent of provider and 24% of consumer respondents did not know if it was desirable to establish a national AT I&R network. They cited such factors as lack of information on the role and functions of a national network, support of existing services, and the ability to help distribute information on a national level. Consistently, it was the respondents' concern that the national AT I&R network address the existing disparity between AT I&R services before giving their commitment of support. As one I&R provider stated the universal concerns of this group of respondents: "I support the need for a national AT I&R network. However, I will not



support an agency that calls itself a clearinghouse for information and then cannot provide the needed information. It needs to provide free services and assurances that the distributed information is accurate and timely. It will succeed only if a national education program is part of their function to reach prospective users of the network. It's shocking to me how many professionals do not know about ABLEDATA or NARIC. I propose that same mistake not be made with a national AT I&R network."

The study participants described the desired activities and functions they would ascribe to a national AT I&R network. The following integrates the findings across all study phases and gives the organizational characteristics participants perceived as desirable.

ASSISTIVE TECHNOLOGY I&R SERVICES

Listed in Table 3 are the types of services offered by AT I&R providers. The overwhelming majority of providers reported that they provide 4 or more of the 10 types of information listed in the questionnaire. The four types most frequently mentioned are Assessment and Evaluation (97, or 56%), Assistive Technology Equipment (97, or 56%), Training on Technology-Related Devices (94, or 54%), and Information on Accessibility (90, or 52%).

Table 3
AT I&R Services Provided By Agencies
N = 174

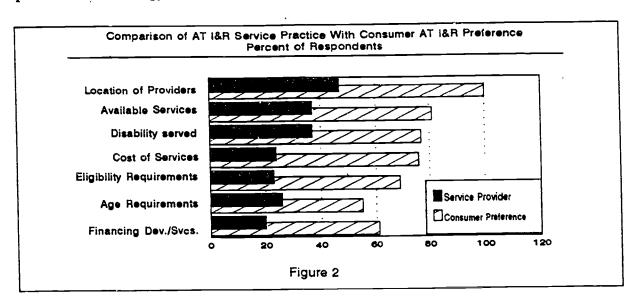
AT I&R Services	Number of Programs	Percent of Respondents
Equipment	97	56%
Assessment/Evaluation	97	56%
Training	94	54%
Accessibility	90	52%
Lease/Rental/Loan	69	40%
Funding	68	39%
Ordering	62	36%
Fabrication	58	33%
Maintenance/Repair	56	32%
Fitting	49	28%
Other	27	15%

The three service areas with the fewest responses were Other (27, or 15%), Fitting (49, or 28%), and Maintenance/Repair Services (56, or 32%). The responses tabulated in the Other category ranged from providing information on reference documents to consultation on technology-related services and devices.

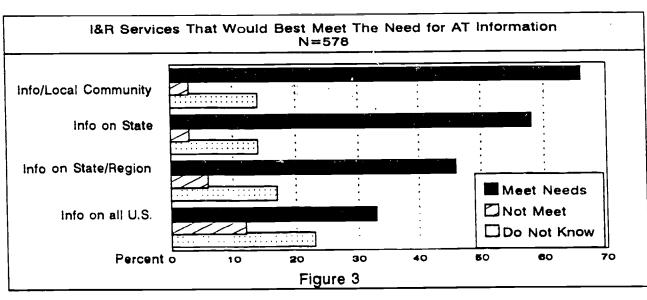
On the surface, a discrepancy exists between the type of information consumers want and that offered by AT I&R providers. In the previous year, consumers cited the five most-frequently needed types of assistive technology-related information to be on devices (288, or 50%), funding for devices (222, or 38%), locating AT services (207, or 36%), specific information on service providers (184, or 32%), and information on disabilities



(176, or 30%). Yet when asked about the desired type of AT information, a discrepancy exists between the thoroughness desired and the accuracy of information provided to consumers by AT I&R services. All consumer respondents (578, or 100%) wanted a contact person, agency name, address, and telephone number with each referral. The four types of most-frequently desired information were a description of services and devices (471, or 81%), types of disabilities served (446, or 77%), cost of service of device (437, or 76%), and how to apply for the service or device (431, or 75%). An analysis of this data suggests that consumers need the ability to access standardized categories. Additionally, consumers want the assurance that minimum standards exist for information distribution across all AT I&R service providers. Figure 2 illustrates a comparison between AT I&R practices and technology-related information desired by consumers.



All study participants affirmed that it is impossible for a single AT I&R service to have at their disposal all the needed consumer information. Although AT I&R services at the local level meet the immediate information needs of most of the 548 study participants (348, or 66%), they did not meet all their needs for information at the state level (79, or 14%), region of the country (100, or 18%), or the United States and its territories (129, or 23%). To meet the diversity of information needs, a coordinated approach must be developed for the delivery of AT I&R services. Figure 3 illustrates the diversity of geographic area information desired by consumers of AT I&R services.



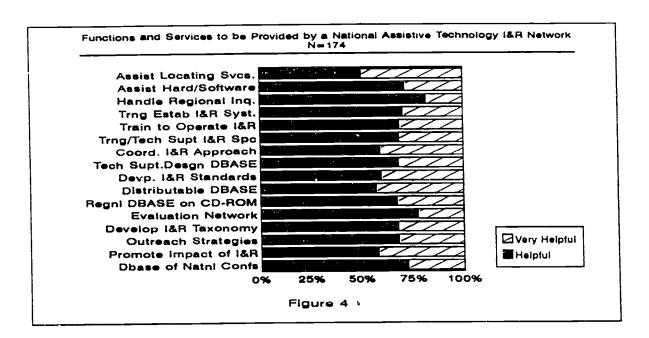


Facilitating a coordinated approach toward the delivery of AT I&R services is the essential function to be performed by a national AT I&R network.

Participants in interviews cite the following as deterrents to using AT TRR services:

- Disparity in the quality of information provided by AT I&R services;
- Inconsistency of information available from differing sources; and
- The differing terminology used by agencies to refer to similar services and devices.

AT I&R providers refer to 16 important functions and services to be performed by a national AT I&R network. These activities range from direct services to consumers, such as help in locating AT I&R services, to indirect services that coordinate the delivery of I&R services. Figure 4 illustrates AT I&R functions and services, and providers' ratings in meeting the needs of consumers.



The feasibility of incorporating these services and functions into a national AT I&R network will be further discussed throughout this chapter.

ACCESS TO AT I&R SERVICES

Unanimously, consumers and I&R providers want increased access to technology-related information services. Access to AT I&R services is broadly defined as the intentional use of methods that make available technology-related information and program referral services to consumers (see Appendix C for a glossary and definition of terms used throughout this report). In the previous year, 62% of consumers reported needing to locate information on assistive technology. The top four formats reported as best for consumers to access AT I&R services are a toll-free telephone number (419, or 72%), printed material or fact sheet format (409, or 71%), a hotline service (152, or 26%), and audio cassette (134, or 23%). The preferred access format is a direct result of the disability of the consumer, their knowledge of AT services and devices, the language spoken at home, their educational level, and their disposable income. As illustrated in Table 4, this finding does not contradict the formats reported by AT I&R providers as used by consumers to access these services.



Table 4
Monthly Individual Contacts to AT I&R Agencies
N = 67,356 Contacts

Contact Method	Number of Individuals	Percent of Response
Telephone (800#)	28291	42%
Telephone (toll)	22514	33%
Mail	7926	12%
Walk-ins	3300	5%
TDD/TTY	2989	4%
Local Call	1436	2%
Computer Access	652	1%
Other	272	.4%

To meet the needs of individuals who may benefit from assistive technology, AT I&R services must employ multiple-access formats. Failure to incorporate multiple-access formats may result in AT I&R services reaching a limited number of consumers. Consumers reached may be those with access to certain formats and not all consumers who can use the information. Key informant interviews with under-represented consumer groups provided insight into this phenomenon. The study documented that under-represented groups are more easily reached through community leaders or organizations and media in their language.

Overwhelmingly, consumers reported that a fee for AT I&R services would restrict access to only those consumers that could pay for the service. In the previous year, 85% of consumers reported not paying for AT I&R services. The willingness to pay a fee was correlated to the consumers' experiences with accessing AT I&R services and the ability to use the information to meet their AT needs.

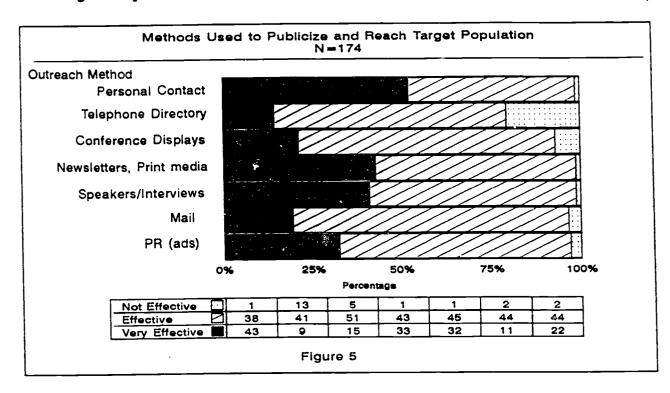
AT I&R CONSUMER OUTREACH EFFORTS

The ability to reach consumers of AT I&R services is the direct result of the outreach method and the designated recipients of the service. AT I&R providers reported using a combination of seven outreach methods to both publicize services and reach the target population. The three methods cited as very effective by provider respondents consisted of personal contact (74, or 43%), newsletters (56, or 33%), and speaking engagements or interviews (56, or 32%).

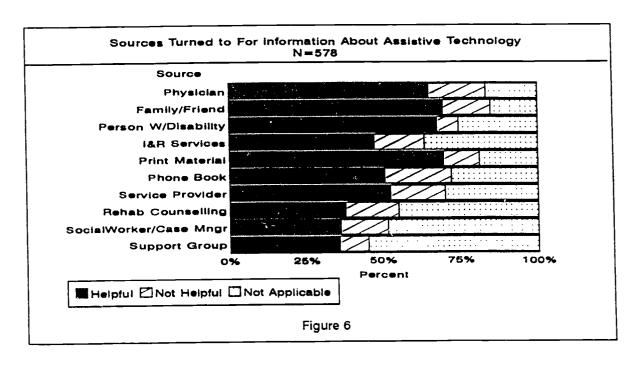
AT I&R providers reach a diverse group of consumers, ranging from individuals with disabilities to legislators. The study documented differences between the types of individuals reported using AT I&R services and those reported using NIDRR State-funded projects. In an average month, 32% (or 6,682) of AT I&R requests to non-State-funded projects were from the public. In contrast, 46% (or 1,536) of AT I&R requests to State-funded projects were from persons with disabilities or their family members. Some reasons for this discrepancy lie with the total mission of the AT I&R service, the classification of these services, and the auspices of their parent



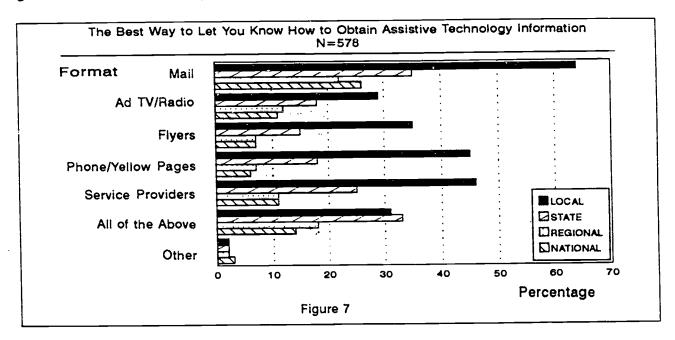
organization. A combination of these factors determines the target population reached and served by AT I&R brokers. Figure 5 depicts the outreach methods used by AT I&R providers.



Consumers reported most frequently turning to physicians, family and friends, persons with disabilities, and printed material for information on assistive technology. They cited these sources as most helpful in learning about AT I&R services and devices (see Figure 6 for a breakdown of consumers' perception of the helpfulness of sources used to gain AT information).



In reviewing this data, the findings indicate that consumers use both traditional and non-traditional sources to locate AT information. To reach consumers it is desirable to employ outreach efforts that incorporate both traditional and non-traditional sources of information. Outreach efforts must consider the geographic region of the target audience. As Figure 7 illustrates, consumers want a strategy that is sensitive to both the geographic region and their individual ability to locate information.



Focus group participants unanimously endorsed a national outreach campaign that focuses on increasing the awareness level of the benefits of using AT services and devices. As illustrated in Figure 6, many of the available traditional information sources are perceived as not applicable in meeting their technology needs. The lack of application of these resources for consumers lies in the lack of exposure to them. This situation may be remedied through an emphasis on outreach methods and strategies that expose consumers to available AT services and devices.

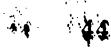
ORGANIZATIONAL STRUCTURE

Organizational structure encompasses three interrelated components (i.e., Organizational Arrangement, Funding, and Staffing). These will be discussed in this section in the context of what the study found to be the most desirable features of each component.

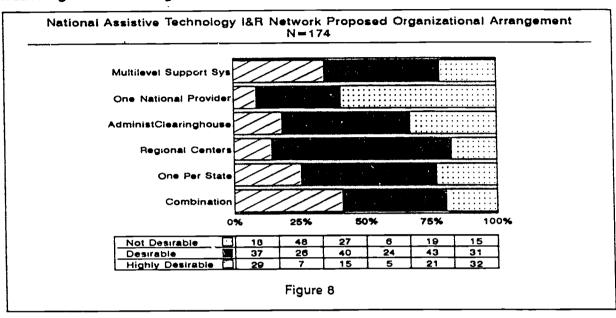
Organizational Arrangement

The study participants unanimously endorsed an organizational arrangement which supports existing AT I&R services. Thus, they rejected any network organizational structure that supplants existing services and attempts to establish a single AT I&R entity. As previously cited, the informational needs of consumers can only be met through a diversity of services providing information across geographic regions and with direct referrals to local services. Providers rated as highly desirable organizational structures which resulted in a combination of services across geographic regions and areas of expertise (56, or 32%), and one national AT I&R provider with a multi-level system of support for local, state, and national systems (50, or 29%). This finding



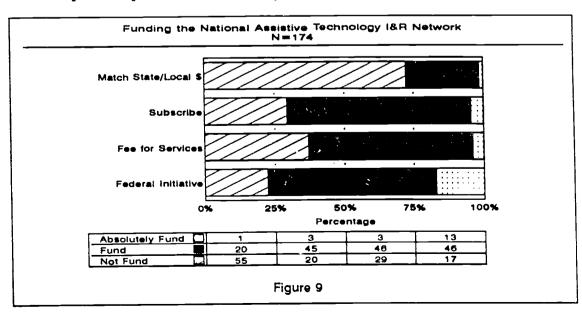


is supported by the caller referral rate of provider respondents (146, or 84%) and State-funded projects (24, or 96%) to AT I&R services outside of their reporting area. Forty-one percent of the total referrals made by AT I&R providers was to I&R services outside of their operating area. Figure 8 depicts AT I&R providers' ranking of alternative organizational arrangements.



Funding

Several alternatives by which to fund a national ATI&R network were explored with both consumers and providers of existing ATI&R services. Consumers strongly felt that a fee for service had the potential to eliminate a segment of the consumer population. However, they supported a minimum fee for some written materials and publications not readily available at the local community level. AT I&R providers would support processes that would not require state agencies to match funding to establish a national AT I&R network. This data was corroborated throughout the study. Fifty-three percent of AT I&F providers cited limited fiscal resources as the most significant factor hindering the establishment of a national AT I&R network. Figure 9 highlights the processes AT I&R providers perceived as desirable by which to fund a national AT I&R network.

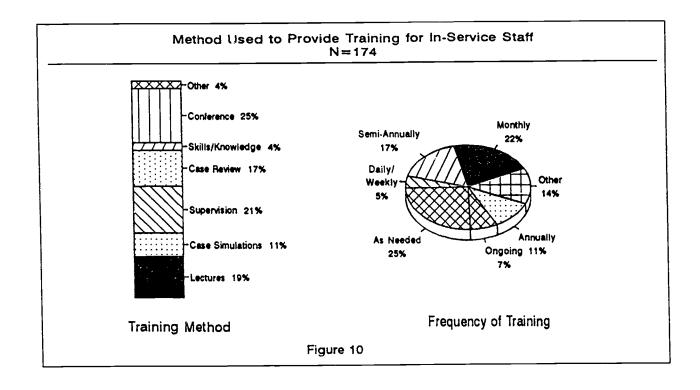




Staffing

The staffing patterns of ATI&R services were a function of both the organizational structure and funding levels. Organizations with a primary focus on the delivery of I&R services tended to hire full-time, paid professional staff to serve as information brokers.

No consistent training or certification program exists for AT I&R staff. The study documented that entry-level and in-service training provided to I&R staff consists primarily of supervised exposure to assistive device databases. A limited amount of training is provided in the areas of listening, assessment, advocacy, and resource-building skills. The greatest gap in training is in the area of follow-up to ensure the accuracy of information provided to consumers. The lack of standards to guide the staffing of AT I&R services can create access difficulties for users. Consumers point to the lack of standards, insensitivity, and inconsistency of information as barriers to meeting their information needs (see Figure 10 for the type of training methods and frequency of training provided to entry-level I&R staff).



This study documents that the lack of uniform organizational structure practices across programs can severely affect the ability of programs to share information. It is desirable to explore the development of minimum standards of practice to guide the staffing and funding of AT I&R services.

THE FEASIBILITY OF ESTABLISHING A NATIONAL AT I&R NETWORK

This section summarizes the study findings in terms of the factors that help or hinder the feasibility of establishing a national AT I&R network. It explores, first and foremost, the feasibility of establishing a network that is responsive to meeting the information needs of consumers. The findings are grouped into four factor areas for examination (i.e., Technology, Training, Taxonomy, and Turf). These four areas are defined as follows:



- <u>Technology</u>: Technological factors that have an impact on the ability of AT I&R services to collect, classify, access, manage, verify, and distribute technology-related information.
- <u>Taxonomy</u>: Technology-related classification terminology and definitions employed by consumers, service providers, and professional disciplines to refer to services, products, or devices. The use of terminology has an impact on the ability to classify, code, organize, and understand distributed information.
- Training: Factors that impact on the ability of organizations to provide and deliver AT I&R services.
- Turf: The ability of organizations to collaboratively exchange information is a direct consequence of their ability to overcome turf issues. Turf issues have the effect of limiting and not expanding the scope of activities. Turf issues impact the ability of organizations and individuals to collaborate and avoid duplication of efforts.

TECHNOLOGY FACTORS

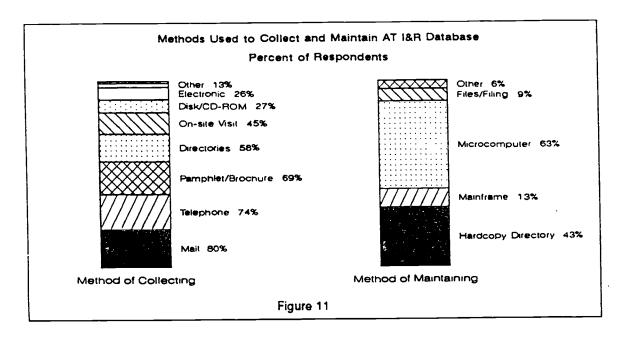
Technology presently exists to link existing AT I&R services through an electronic network. However, it is not desirable to electronically integrate existing systems due to two key factors which can seriously impeded consumers' access to timely and accurate information. Each factor is discussed in detail in this section.

Factor 1: Information Management

The diversity of hardware platforms used by existing AT I&R systems poses some challenges for information collection, classification, and management and distribution of the data. The study documented that. of 174 AT I&R providers, 60% (or 105) of the respondents used an IBM hardware platform for information management. The IBM platforms ranged from simple computers (IBM XT models) to powerful machines capable of handling vast amount of information (IBM-compatible 486, 33 mhz, with a 105 hard-disk drive). This same diversity was present among providers using an Apple hardware platform (61, or 35% of the respondents). It was found that even when providers used the same hardware platforms they did not use the same software programs. The study documented that, among the 174 respondents, a total of 45 different software application programs were used to manage information. The lack of compatible hardware and software can seriously impede the ability to transfer and share data from one I&R service to another. Data transfer is a rigorous and time-consuming task between AT I&R systems using different hardware and software platforms. The time required to complete this task can result in interfering with consumers' access to timely, accurate information. Additionally, the reliance of individual AT I&R systems on differing software can severely limit the ability to access other information databases. This can ultimately restrict consumer access to only those systems with similar applications and interfaces. As an example, without a requirement to standardize AT information databases, one may be able to access one application and not have access to similar applications.

Presently, there are no uniform standards for data collection and maintenance of information provided by assistive technology information and referral programs. The tendency toward using printed media can result in the reliance on information that is outdated by the time it is distributed to consumers. Although electronic data communication provides a more timely distribution of information than printed materials, it is not widely used among AT I&R providers. As illustrated in Figure 11, providers strongly rely on publications to collect and maintain their AT I&R databases.





Forty-three percent of providers (74 of 174) reported sharing their AT I&R databases with other I&R services. The two methods frequently used to share data were through printed media (61 out of 74 respondents) and electronic media (58 out of 74 respondents). Electronic media is defined as floppy disks (28 out of 74 respondents), modem (20 out of 74), and CD-ROM (11 out of 74). Specifically, the data suggest that in the current state of AT I&R practice there is a reliance on printed materials over electronic media.

The researchers tested the feasibility of electronically linking four different assistive technology databases. The four database systems selected were the following: HyperABLEDATA; Adaptive Device Locator System (ADLS); IBM National Support Center for Persons with Disabilities; and SpecialTech. These were chosen because their software and hardware platforms reflected the current state of practice and their use as supplental databases by AT I&R providers. The top three supplemental databases used by all AT I&R providers are ABLEDATA (53, OR 54%), NARIC (31, or 18%), and ERIC (25, or 15%). It was found that these database systems could be electronically linked; access to the data, however, was dependent on the communication package. As an example, a sophisticated communication package with graphics can access HyperABLEDATA or ADLS on AppleLink from a remote site. However, these systems could not be used with a simple communication package lacking the capability to display graphics. This examination highlights the feasibility of linking existing systems! However, it is not desirable to do so without first addressing the disparity. between what is desirable and the current state of AT I&R practice.

This finding was supported in a review of the I&R activities of the RESNA Technical Assistance Project to State-funded programs. It was found that even when projects share similar hardware and software platforms and are linked via an electronic network they do not readily share information through a network. The State-funded projects are all electronically linked via the AppleLink network. Yet, of the 64% State-funded projects who share their databases (16 out of 25), only 17% (4 programs) do so through a modem (or electronic network). Several reasons may account for this phenomenon (i.e., the developmental stages of the programs, familiarity with the value of using an electronic network, and the I&R staffing patterns of each program). The study findings indicate that the current state of information management practice among AT I&R providers would not support electronically linking these services. Prior to this action, guidelines and standards must be developed to guide information management among members of the network. Additionally, AT I&R providers must receive training on both the value and ways of sharing information via an electronic network.



Factor 2: Organizational Structure

There is no uniformity across the organizational structures of AT I&R services. As noted on page 13, the lack of consistent organizational practices across services can severely impact on their ability to share information. As a result, there is no correlation between the purpose of the organization, staffing patterns, budget, services provided, and recipients of the service. This finding was consistent across services with similar funding streams and missions. Table 5 illustrates a review of the organizational structures of three State-funded projects. These programs were selected at random from a total of 25 State-funded programs who participated in this study. It should be noted that all the information represented in this table was directly provided by each of the programs in response to the <u>Practices In The Assistive Technology Information and Referral Field Survey</u>.

The differences in the organizational structures of these programs are a result of the available AT resources, target population, and beliefs about the function and practice of I&R services. These differences cannot be disregarded or eliminated in developing AT I&R services that are responsive to the needs of the community. However, it is feasible to develop minimum standards for the training of AT I&R staff and to guide the information and referral process. This will require that a coordinated approach be employed toward the delivery of AT I&R services, with emphasis on the training of AT I&R staff and the establishment of minimum standards to guide information management. The lack of minimum standards in these areas is a critical gap in meeting the information needs of consumers. To electronically link these programs without first addressing these concerns would not increase consumer access to technology-related information. The consumer perspective phase of this study documented that resolving these concerns is pivotal to meeting their technology information needs.

TAXONOMY FACTORS

The study documented that, currently, no assistive technology standardized classification terminology and definitions are used by consumers, service providers, or professional disciplines. This results in the use of several terms to refer to similar services, products, and devices. A common terminology or taxonomy is needed to simplify linking AT I&R systems electronically. Failure to do this can result in gross misinterpretation and corruption of data. Information is useful when individuals have a clear understanding of the terms or language utilized. Presently, 63% of AT I&R providers (110 out of 174) do not use a standard taxonomy for information management. This finding is consistent with State-funded projects, who reported predominantly using a customized or individually-created classification system. AT I&R services cannot be linked electronically without first establishing a common taxonomy and thesaurus of terms.

A comparison of 10 assistive technology services' taxonomies was conducted to test the ability to exchange information among the programs (see Appendix D: Service Taxonomy Comparisons). Not all programs used the term "assistive technology" to refer to technology-related services and devices. It was found that these providers used the terms "assistive technology", "specialized equipment", "assistive technology and equipment", and "specialized medical equipment" interchangeably to refer to assistive technology services and equipment. This inconsistency was found to exist across all the AT I&R services examined by this study. It significantly impacts on the ability of consumers to access, receive, and use information provided through AT I&R services. Additionally, it creates confusion between and among consumers, service providers, and funding sources as to what constitutes assistive technology and its applicability in the daily lives of persons with disabilities. Prior to electronically linking AT I&R services, a common taxonomy and thesaurus of terms must be developed to ensure the accuracy and quality of information provided through AT I&R services.



Table 5
State Funded Programs

Program	New Mexico Assistive Technology Project	Kentucky Assistive Technology Service	Nebraska Assistive Technology Project
Classification of AT I&R Service	Formally designated service of the agency	Formally designated service of the agency	Central Focus and responsibility of the agency
Staffing of AT I&R Services	Admin. staff = 1 Full Time I&R Specialist = 1 Full Time Support Staff = 1 Full Time		I&R Specialist = 1 Full Time Support Staff = 1 Full Time = 3 Volunteers
Budget	\$500,500	\$500,000	\$525,000
Number of years in operation	1.5 years	2 years	2 years
AT I&R Services concentration	Adaptive Equipment Computer Employment Assistive Technology Services Support Services Other Related Services	Adaptive Equipment Assistive Technology Services Support Services	Adaptive Equipment Computer Assistive Technology Services
Number of average monthly requests	157 requests	140 requests	214 requests
Methods used to access AT I&R services	Telephone (800#) Telephone (toll call) TDD/TTY Mail Computer Access	Telephone (800#) Telephone (toll call) TDD/TTY Mail Walk-in	Telephone (800#) Telephone (toll call) TDD/TTY Mail
Recipients of AT I&R services in an average month	General Public Person with disability/their family Advocacy Organization Direct Service Provider Planning/Administrative Staff State Agency Medical Personnel	General Public Person with disability/their family Advocacy Organization Direct Service Providers Planning/Administrative Staff	General Public Person with disability/their family Advocacy Organization Direct Service Provider Medical Personnel
Training activities for AT I&R staff	Entry level - On-the-Job training Inservice training - Monthly	Entry level - two day seminar Inservice training - as needed	Entry level - none Inservice training - as needed

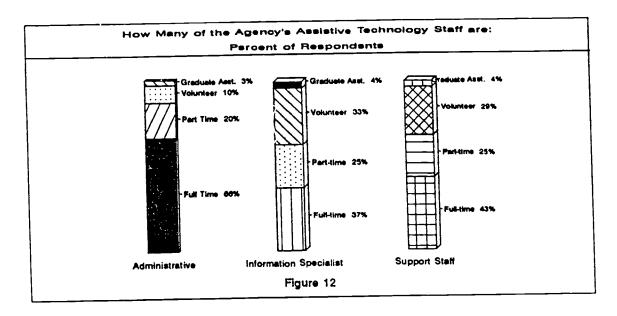


The communication barriers between agencies and consumers can be significant. Consumers stressed the need to eliminate technical jargon and use terms that are clearly defined and consumer-friendly (i.e., clear, non-discriminatory, and universally understood by consumers). A national media campaign can help to create a common frame of reference on what constitutes assistive technology services and devices.

TRAINING

The consumer perspective phase of this study found that consumers experienced lengthy waits for inconsistent services. They reported the inability of information providers to communicate effectively with consumers due to limited experience and technical knowledge about assistive technology and I&R practices. Consumers cited difficulty in effectively communicating with I&R staff members who provided piecemeal information. They reported dissatisfaction with the lack of information available on how to evaluate the quality of trechnology-related services and devices. The primary barrier to communication lies with the absence of materials that provide consumers with quality indicators by which to measure, evaluate, and utilize assistive technology devices and related services.

An analysis of the reported staffing and training practices of AT I&R staff supports the findings of the consumer phase of this study. It was reported that the majority of all AT information specialist positions (62%) were staffed by part-time workers, volunteers, or graduate assistants (see Figure 12 for a breakdown of the staffing patterns of AT I&R services). This staffing pattern is a reflection of the funding levels of AT I&R programs and the lack of minimum standards for information specialists.



A review of training practices indicates that 59% of the providers (104) offer training to entry-level information specialists. However, the training offered is geared toward understanding and working with an informational database, not on facilitating access to technology-related information. In-service training is provided sporadically and without a link toward building information dissemination skills. Overall, the study found that AT I&R providers correlated the lack of training or expertise of I&R staff with four factors that interfered with their ability to meet the goals of the agency. These four factors are presented in rank-order of importance to AT I&R providers:

1. The lack of standardized AT I&R systems, which makes it difficult to provide training across public or commercial databases using different hardware and software platforms.

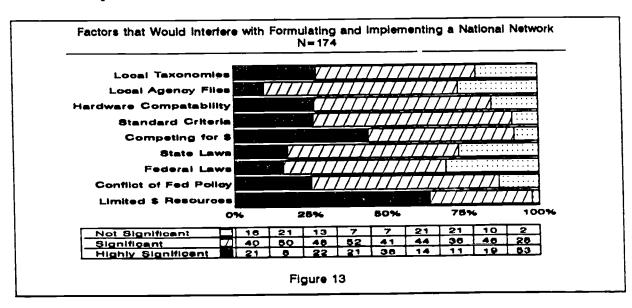


- 2. The difficulty in maintaining, evaluating, and up-dating an ATI&R database to ensure the timeliness and accuracy of information. These tasks are extremely time-consuming, requiring manpower resources not readily available at the program levels.
- 3. Area resources are not always available, requiring I&R specialists to have a comprehensive understanding and knowledge base of services across geographic regions. This level of expertise is not easily achieved with part-time and volunteer staff who are restricted by time and financial considerations.
- 4. The turnover rate of information specialist staff is a consequence of salary levels and the lack of professional accreditation afforded this position.

In order to overcome these barriers, technical and training support must be provided to existing AT I&R services. Additionally, a toll-free telephone information system must be developed that is staffed by information specialists trained to handle requests from consumers, individual professionals, and agencies. This system can serve to close the information gaps found at local community levels. The toll-free telephone information system would make cutting-edge information available to callers and provide referrals to technology-related services throughout the country. This system would address the need for timely, accurate, and comprehensive information on assistive technology. The RESNA Technical Assistance Project has helped heighten the awareness of Statefunded projects of the necessity to train information specialist staff. However, the project is not designed to develop training but, rather, to provide technical support in meeting the needs of the projects. A review of the training provided through the Technical Assistance Project indicates that the request for I&R-related training was focused more on using assistive technology device databases and less on information and referral skills. Overall, the focus of the Technical Assistance Project has not been in the area of information and referral practices. The efforts of this project have been concentrated on facilitating the overall management of State-funded projects and not on helping to coordinate the delivery of AT I&R services.

TURE

The study found that it is difficult for AT I&R services to initiate efforts to collaborate and provide a unified approach to the delivery of AT I&R services. Providers refer to six major factors as possibly interfering with the establishment of a national AT I&R network. Figure 13 depicts the factors that would interfere with the formulation and implementation of a national network.





The three factors cited as highly significant are limited fiscal resources to fund both state and national systems (91, or 53%), competing for fiscal resources (64, or 38%), and lack of hardware compatibility (36, or 22%).

In an environment of limited fiscal resources, the coordination of a national AT I&R network is possible only through strengthening local initiatives. Failure to build upon the strengths of existing AT I&R services will only result in creating a superstructure that is not responsive to the technology information needs of consumers.

SUMMARY

This study determined that it was both desirable and feasible to create a national AT I&R network. The feasibility of establishing this network was examined from both the current state of AT I&R practice and the AT I&R needs of consumers. This chapter provides a summary of the issues that have helped to formulate the recommendations of the study. Subsequent chapters detail the framework and strategies for implementing this network.



Chapter Four

CONCLUSIONS AND RECOMMENDATIONS

he purpose of this study was to determine the feasibility and desirability of establishing a National Assistive Technology Information and Program Referral Network. The study found that it is feasible and desirable to establish a national AT I&R network. Broad support was documented for establishing this network. The findings suggest that existing services do not meet all the technology-related information needs of either consumers or service providers (see Appendix E: Technology-Related Information Needs of Providers and Consumers for a summary of the identified information needs of these two groups). Presently, two factors account for this predicament:

National

ATIER

provide

the framework to meet

the study

findings.

Network:

- The dissemination of technology information lags behind the application of the technology itself; and
- The lack of standardized procedures to guide the delivery of AT I&R services to ensure that consumers receive quality information and program referral services.

Assistive technology information brokers deliver I&R services without consistency. The inconsistencies are exemplified by divergent approaches in personnel practices and methods by which to manage the information and program referral process. Additionally, many AT information by the provide median resources within the confiners of limited funding resources.

information brokers struggle to provide quality services within the confines of limited funding resources. Funding for AT I&R services was found to be inadequate to meet the increasing need for information. This situation is further complicated by the lack of formal mechanisms to channel consumers to appropriate information resources. As a result, barriers have been formed that restrict consumers from accessing needed information and limit the ability of providers to meet the needs of consumers.

Technology-related State-funded projects provide some resources that address the AT information needs of consumers. These projects have placed information resources within the reach of many individuals who previously lacked this information. Still, not all technology-related information needs can be met at the local or state level. This study documented that 96% of technology-related State-funded projects refer consumers to information resources outside their operating areas. Seventy-two percent of these referrals were made to regional and national I&R services. These figures support the need to provide information brokers that can meet the needs of consumers across various levels (i.e., local, state, regional, and national).

The results reflect the timeliness of this study and the importance of NIDRR taking a major leadership role in determining the future of AT I&R services. The passage of the Americans with Disabilities Act, along with the rapid pace of technology, will advance a "decade of information explosion" for individuals with disabilities. This growth will require that I&R services have the capacity to link consumers with needed information. To meet this challenge, a national coordinating system must be created to correct deficiencies and build upon the strengths of present AT I&R services. This challenge must be addressed now. The study documents that AT I&R services are at a critical junction of development; they can continue to grow in an uncoordinated fashion of commit to advance the practice of AT I&R services. A national priority to improve AT I&R services will result in meeting the technology-related information needs of consumers. Under the leadership of the U.S. Department of Education, the time is now.

ERIC Fronted by ERIC

A strong leadership role by the U.S. Department of Education can result in creating linkages between persons with disabilities and needed services. AT I&R services play a key role in meeting the intent of the Technology-Related Assistance for Individuals with Disabilities Act. AT I&R services as a national priority bring into focus the impact of information on meeting the needs of consumers for technology-related services. This can serve as the catalyst for exploring public- and private-sector initiatives and bring visibility to the effects of technology on individual lives. This focus is essential to resolve the questions of what is appropriate to fund and what services and devices can best meet the needs of consumers.

In response to the major findings of the study, the following recommendations are made to NIDRR. The recommendations are grouped into five major areas: Policy; Coordination of AT I&R Services; Information Management; Staffing of AT I&R Services; Outreach; and Promoting AT I&R Services.

POLICY RECOMMENDATIONS

- 1. Establish a national AT I&R network to help coordinate and disseminate information on technology-related assistance for persons with disabilities.
- 2. Commit the necessary federal resources to implement strategies to improve the current state of AT I&R practices.
- 3. Commit the necessary resources to improve the delivery of ATI&R services at the federal, state, and local community levels.
- 4. Convene a national meeting of federal agencies to develop strategies designed to help coordinate and improve the delivery of I&R services.
- 5. Convene a National Assistive Technology Information and Program Referral Commission to develop strategies for improved coordination of technology-related services. This commission should include representatives from consumer groups, professional associations, public-sector agencies, private non-profit agencies, private for-profit companies, and I&R practitioners.
- 6. Establish a national AT I&R toll-free telephone number to link persons with disabilities and AT services providers with appropriate resources. This service must be accessible in a variety of formats and provide linkages to referral at the local and state levels.
- 7. Establish a national assistive technology evaluation project to provide indicators to help consumers determine the quality and applicability of services and devices in meeting their technology needs.
- 8. Conduct field initiated research of I&R "best practices" and their application in the dissemination of AT information.
- 9. Develop a national classification "taxonomy" for the delivery of AT I&R services.
- 10. Conduct a national awareness campaign on assistive technology with parallel emphasis on I&R activities at the regional, state, and lwocal levels. The target population of this campaign will be consumers of technology-related services, with emphasis on reaching both formal and informal resources utilized by persons with disabilities.



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- 11. Develop a national resource and technical support coordinating institute to:
 - Facilitate a coordinated approach for the delivery of AT I&R services.
 - Provide technical support to AT I&R services.
 - Develop national training materials to enhance the delivery of AT I&R services.
 - Provide training to enhance the capacity of I&R staff to deliver AT I&R services.

COORDINATION OF AT I&R SERVICES RECOMMENDATIONS

- 1. Implement coordination strategies that build upon cooperative agreements between federal agencies providing I&R services, institute standards of performance for the provision of AT services, and other mechanisms to enhance coordination of technology-related information for persons with disabilities and their families.
- 2. Develop a technical assistance manual for the coordination of AT I&R services, which details strategies within the context of the options available to deliver I&R services.
- 3. Provide leadership to develop a National Assistive Technology Information and Program Referral Coordinating Institute. NIDRR will provide the oversight for the activities of the Coordinating Institute.
- 4. Develop and implement a plan for a fully-coordinated AT I&R delivery system, with centralized functions providing technical support needed by community AT I&R services.
- 5. Develop and implement initiatives that recognize the value of I&R services and build support for a coordinated system.

INFORMATION MANAGEMENT RECOMMENDATIONS

- 1. Establish a mechanism to review, modify, or adapt the "Standards for Information and Referral" and the "Taxonomy of Human Services", developed by the Alliance for Information and Referral Systems, for use by NIDRR-funded AT I&R services. If adaptation is not feasible, develop standards and an assistive technology services taxonomy.
- 2. Provide the technical and training support for projects to implement minimum standards on information management and a taxonomy for the delivery of AT I&R services.
- 3. Establish annual priorities for field initiated research on the best practices in the delivery of AT I&R services.
- 4. Establish a mechanism to examine hardware and software options for all NIDRR-funded AT I&R services and determine their suitability, strengths, and weaknesses.
- 5. Develop guidelines and options for the selection of computer hardware and software to maximize compatibility among AT I&R services. The lack of compatibility can severely restrict the ability to electronically link AT I&R services.
- 6. Provide technical support to AT I&R services in the selection and utilization of computer hardware and software.

7. Develop consumer-responsive guidelines and evaluation strategies to measure the effectiveness of AT I&R services.

STAFFING AT I&R SERVICES RECOMMENDATIONS

- 1. Establish mechanisms to develop minimum competency guidelines for AT I&R staff.
- 2. Develop mechanisms to provide technical and training support for AT I&R services and I&R staff to implement the following:
 - Implementing standards;
 - Utilizing an AT I&R Services Taxonomy;
 - Meeting minimum competency levels; and
 - Developing in-depth expertise in various health and human service programs and technology-related issues.
- 3. Develop mechanisms for sharing training materials, innovative approaches, strategies, and technological applications.

OUTREACH RECOMMENDATIONS

- 1. Establish mechanisms to develop and implement minimum standards of evaluation on the effectiveness of AT I&R services.
- 2. Develop outreach partnerships with corporations, public and private organizations, broadcast media, civic associations, and other groups to launch a national awareness campaign on assistive technology.
- 3. Establish demonstration projects to test innovative approaches to underserved and under-represented groups by AT I&R services.
- 4. Establish a mechanism to provide technical support and training on outreach strategies with formal and informal information brokers.
- 5. Provide the technical support and resources to AT I&R services for developing outreach strategies with underserved and under-represented groups.

PROMOTING AT 1&R SERVICES RECOMMENDATIONS

- 1. Initiate local community promotional campaigns that parallel a national assistive technology awareness campaign. Local community promotional campaigns can include public service announcements, video productions, and printed media.
- 2. Establish statewide 1-800 ATI&R telephone numbers. The state numbers are an essential link between the national 1-800 system and local communities.

Subsequent sections of this chapter are used to formulate guidelines for establishing a national AT I&R network.



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DEFINING THE NATIONAL ASSISTIVE TECHNOLOGY INFORMATION AND PROGRAM REFERRAL NETWORK

The creation of a National Assistive Technology Information and Program Referral Network can begin to provide the framework by which to address the study findings. The challenge for the researchers was to integrate the diversity of views and recommend a network that could meet the technology-related information needs of both consumers and providers. A network designed to be both multi-faceted and evolving can meet this challenge. The design must encompass an implementation plan that details the activities to be enacted within a designated time period. Establishing a national AT I&R network that evolves in a systematic and planned manner overcomes the barrier of attempting to meet the information needs of every group at the outset. A plan that evolves over time by identifying and building on the current state-of-practice of AT I&R services can result in a network system that is truly responsive to the needs of its consumers. It is within this context that the following framework is explored. The framework is organized into three categories: Role of the National AT I&R Network. Organizational Arrangement, and the Centralized Components of the National AT I&R Network.

Role of the National Assistive Technology Information and Program Referral Network

The National Assistive Technology Information and Program Referral Network should encompass individuals or organizations that seek to help distribute information areas affecting individuals with disabilities. The information should be focused on available efforts that seek to enhance the quality of life of individuals with disabilities. The use of this broad network definition allows for diversity of membership. This membership can include individuals, agencies, or organizations that both use and need assistive technology-related information.

The mission will be to disseminate information on technology-related assistance for individuals with disabilities. This network can use electronic and non-electronic systems, including, but not limited to, telephones, computers, mailings, interview television, and other media, to fulfill this mission. The network shall be readily and easily accessible to all interested parties, including consumers, their families, professionals, and the public.

Membership in this network will comprise national and local resources established to assist individuals with disabilities. The success of this network will rest with the ability to attract members representing both traditional and non-traditional sources of information dissemination. Thus, members may include, but are not limited to, state and national organizations/programs, local centers/programs, or individual community resources.

Organizational Arrangements

This study documented a diversity of organizational structures across agencies delivering AT I&R services. Participants in the survey "Practices In the Assistive Technology Information and Program Referral Field" classified their AT I&R services in one of the following ways:

- The central focus and responsibility of the agency;
- A formally designated service of the agency; or
- Not a formally designated service, but provided as requested or as needed by consumers.



It was found that no correlation exists between how an agency classifies its AT I&R service and such factors as:

Annual budget

• Population served

• Staffing patterns

• Number of I&R requests

Geographic area served

• Information Management Practices

Thus, even when agencies classified their ATI&R services in a similar fashion, the services varied greatly in range, scope, and quality. The ideal or optimal organizational arrangement for the delivery of ATI&R services does not exist. A variety of organizational arrangements and organizational structures exists which individually attempt to meet the information needs of their target populations. These organizational arrangements range from generic one-person, one-telephone services to complex national specialized systems that handle hundreds of inquiries a day. The organizational structures of the ATI&R services studied ranged from independent, single-agency, autonomous services to interdependent, multi-agency ATI&R services. A summary of the types of organizational arrangements is illustrated in Appendix F. The data in Appendix F is comprised of 9 programs selected at random from the 174 information brokers who participated in this study.

PROPOSED ORGANIZATIONAL ARRANGEMENTS FOR THE NATIONAL ASSISTIVE TECHNOLOGY INFORMATION AND PROGRAM REFERRAL NETWORK

Based on a review of existing organizational arrangements of AT I&R services, the participants in the regional focus groups and the members of both the Consumer Advisory Group and the Expert Panel Groups proposed the following organizational models: Decentralized; Centralized; and Facilitative. These models were seen as viable organizational arrangements for the proposed National Assistive Technology Information and Program Referral Network.

Alternative 1: Decentralized Network

A decentralized network is comprised of ATI&R services and agencies whose individual organizational structures may vary, ranging from free-standing autonomous services to services that are sub-units of multifunctional agencies. The members of a decentralized network would not have to share the same funding levels, source(s) of funding, target population, or services. No single AT I&R would assume total responsibility for conducting AT I&R services; the responsibility would be shared by all the members of the network.

However, it was proposed that one NIDRR-funded AT I&R project assume responsibility for coordinating the activities of the AT I&R network members. The coordinating responsibility would be held by different projects on a rotating basis. These coordinating projects would ensure inter-organizational coordination among the members through cooperative agreements and informal decision-making processes.

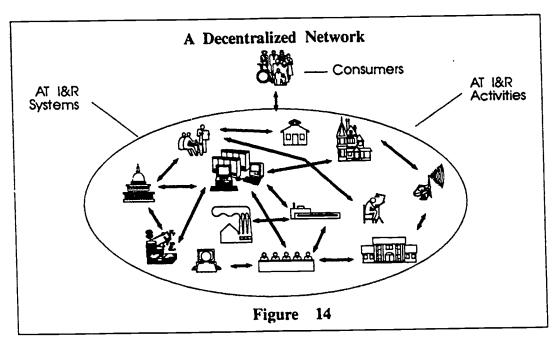
The proposed decentralized system was perceived as viable for the following reasons:

- A. Bridging the need for autonomy among members of the proposed network.
- B. The potential exists for developing cooperative and collaborative initiatives that impact all the members.



- C. Rotating the responsibility for coordination among all members without any one member taking responsibility for the scope of the activities.
- D. Establishing grassroots leadership for the accomplishment of initiatives and activities.
- E. Allowing varying degrees of specialization among its members.

Thus, the AT I&R function would be provided across various levels of the service delivery system (i.e., local, state, regional, and national). Utilizing this organizational arrangement, the elements comprising the National Assistive Technology Information and Program Referral Network could be dispersed among all members of the network or assigned to certain members as part of their funded activities. Figure 14 illustrates the proposed working model of a decentralized network.



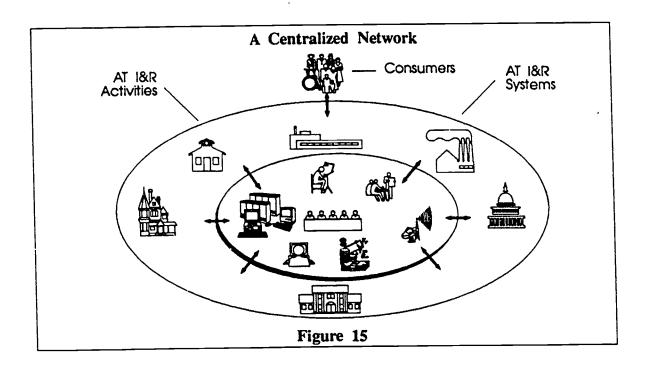
Alternative 2: Centralized Network

A centralized network of ATI&R services and agencies would differ from a decentralized organizational arrangement in the following ways:

- A. Coordination responsibility would be based primarily in a single agency funded to carry out collaborative activities and initiatives among network members.
- B. AT I&R services would be centralized.
- C. Specialized activities would be centralized in one agency (e.g., training of I&R specialists).
- D. The coordination and specialized activities would be directly accountable to one funding source for monitoring and compliance purposes.

A centralized network system was perceived as providing consistency and greater accountability among its members. This organizational arrangement would lend itself to providing a coordinating structure that is easier

to manage, more definable, and measurable. Additionally, there would be greater assurance of consistency of services among all network members. Figure 15 illustrates a proposed working model of a centralized network.



Alternative 3: Facilitative Network

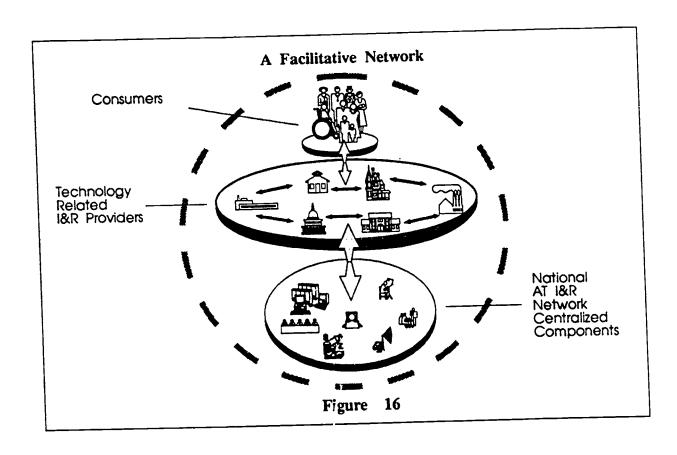
The facilitative network arrangement was first introduced by Austin (1979) as an alternative concept that emphasized flexible linking among network members rather than requiring the members to change the aims of the network. An adaptation of Austin's original model can result in the development of a network that can combine the "most appealing" attributes from both the decentralized and centralized network models.

A facilitative network would differ from the centralized and decentralized models in the following manner:

- A. The autonomy of members would be ensured through the provision of AT I&R services across multi-levels. A centralized national AT I&R service would be established to serve as an entry point for national services. Thus, the responsibility for the delivery of AT I&R services would be distributed across all members of the network.
- B. Coordination activities would be the responsibility of all members. However, single agency(les) would be funded to develop, implement, and evaluate the specialized activities listed under the elements comprising the AT I&R network.
- C. Governance of the AT I&R network would be the responsibility of the funding source. However, oversight would be provided by a committee comprised of mambers of the network, consumers of the network, and public- and private-sector interest groups.



The research team of this study believes that the facilitative network organizational arrangement model can best meet the proposed mission of the National Assistive Technology Information and Program Referral Network. This model can successfully address the information and quality assurance needs identified throughout this study. It can also provide the needed autonomy for individual members to address the specialized needs of their target populations. The use of supportive mechanisms would help to facilitate the development of all members, regardless of their stage of development, agency size, or funding source. Most importantly, a facilitative network would have the potential to address the needs of consumers for quality, accurate, and timely AT I&R services. Figure 16 illustrates a proposed working model of a facilitative network.



The Centralized Components of the National AT I&R Network

The existing literature details the factors that promote networking among I&R services. The preeminent factor is to adopt during planning a strategy that promotes the interests of all members of the network. Given the documented disparities that exist within and between I&R services, successful implementation of a National AT I&R Network will require that strategies be developed to meet identified needs.

For purposes of this report, the recommendations of the proposed network have been grouped into two functional areas: Activities currently funded by the National Institute on Disability and Rehabilitation Research (NIDRR) as autonomous initiatives and activities not currently funded by NIDRR as autonomous initiatives.



- A. Recommended activities currently funded by NIDRR as autonomous initiatives include the following:
 - 1. A distributable AT I&R database
 - 2. A regional AT I&R database on CD-ROM or other formats
 - 3. A distributable database of AT I&R conferences at local, state, regional, and national levels
 - 4. A database of assistive technology devices and products

It is recommended that NIDRR continue to fund these activities under current funding initiatives. However, new funding cycles must place emphasis on the contractor's responsibility to disseminate the products of these activities in a timely, accurate, accessible, and affordable manner. Presently, all of these activities exist in some form as part of the scope of activities funded by NIDRR. As an example, HyperABLEDATA, a distributable database of ABLEDATA, is currently available on assistive devices. The research study documented the need for these activities to be more responsive to using methods that expand dissemination, outreach, and accessibility to potential recipients of these services. This recommendation would require NIDRR to place an increased emphasis on the ability of the contractor to disseminate, publicize, and make accessible these products to a wider constituency of consumers and providers of technology-related information. Care must be taken by contractors to ensure that all products are user-friendly or that trained personnel are available to respond to inquiries.

- B. Recommended activities <u>not</u> currently funded by NIDRR as autonomous activities have been grouped into six centralized components. They are the following:
 - 1. Assistive Technology Information and Program Referral Coordinating Institute
 - 2. 1-800 Telephone Number: Assistive Technology Information and Program Referral System
 - 3. Assistive Technology Services and Devices Evaluation Project
 - 4. Assistive Technology I&R Field Initiated Research and Innovation Projects
 - 5. National Assistive Technology Public Awareness Campaign
 - 6. Assistive Technology Information and Program Referral Services Taxonomy Project

The proposed activities remain combined into these six centralized areas. These area groupings do not imply that their implementation will be the responsibility of a single entity. A separate section will examine the desirable organizational funding structures proposed by the participants of this study. These activities have been proposed to meet the findings of this study.

B1: ASSISTIVE TECHNOLOGY INFORMATION & PROGRAM REFERRAL COORDINATING INSTITUTE

ACTIVITY (ies):

The National Assistive Technology Coordinating Institute provides direct and indirect services. Direct services are those which have an immediate impact on the delivery of AT I&R services. Indirect services are those which support the delivery of AT I&R services.

- a. Indirect Services
 - i. Play a lead role in coordinating a unified approach to AT I&R service delivery.
 - ii. Assist in developing an AT I&R services taxonomy (classification system), definition of terms, and thesaurus.



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- iii. Assist in developing an evaluation network for local and regional AT I&R systems.
- iv. Provide technical support for designing an AT I&R database structure.
- v. Develop AT I&R standards for data compatibility and data interchange at all national levels.

b. Direct Services

- i. Provide training and technical support for AT I&R specialists.
- ii. Provide training in operating an on-line AT I&R service.
- iii. Provide training on how to establish and integrate research on operating an AT I&R service.
- iv. Provide guidance with hardware/software selection through an annual conference and fact sheets listing available I&R software and hardware.
- v. Develop and disseminate training modules on the delivery of AT I&R services for information brokers.

Some of the activities contained in this area are interdependent. Thus, implementation may require further classification beyond the direct and indirect service roles presently assigned (e.g., Direct Service: Provide training for I&R personnel that might include all the activities dealing with training). The decision to further group activities may be a function of the funding stream and the organizational arrangements of the proposed network.

B2: 1-800 TELEPHONE NUMBER: ASSISTIVE TECHNOLOGY INFORMATION AND PROGRAM REFERRAL SYSTEM

ACTIVITY (ies):

Establish a 1-800 telephone number service to serve as a referral point to available AT I&R providers and provide information not available at the local, state, or regional levels.

a. Types of Information to be Provided

The 1-800 telephone number service can maintain and disseminate the following types of information:

- i. Information on AT L&R services available throughout the United States
- ii. Information on federal legislation affecting AT I&R services
- iii. Information on technology-related services and devices
- iv. Information on funding sources (i.e., general and at community levels for technology-related services and devices)
- v. Information on training and program materials affecting the dissemination and delivery of information services

It is essential that this information be available through multiple-access and alternate formats to include, but not be restricted to, an on-line database, a 1-800 number, printed materials, and fact sheets. A detailed discussion of the need for multiple-access and alternative formats is found on page 16.



b. Proposed Organization of the AT I&R Database

The study found that the types of technology-related information most often sought by consumers and to be maintained by the National AT I&R 1-800 telephone number service are the following:

- i. Agency and program general information
 - Agency and program name(s) (common name and acronym)
 - Mailing address, city, county, state, and ZIP code
 - Local address, city, county, state, and ZIP code
 - Telephone, toll-free, TDD, and fax number(s)
 - Name of Agency/Program Director, Referral, and Grievance Contact Person(s)
 - Accessibility of the service site
- ii. Description of the service or device
 - Name of the service or device
 - Description of the service or device
- iii. How to apply for services, the referral process, and documents required
- iv. Types of disabilities/conditions served
- v. Cost of service/device
 - Fee schedule
 - Associated costs
- vi. Funding for service/device
 - Type of payment accepted (i.e., insurance, credit card, check, loan, lease, and others)
 - Availability of financial assistance
 - Funding legislation
- vii. Eligibility requirements and length of time on a waiting list
- viii. Ages and genders served
- ix. Hours of operation and time zone
- x. Geographic area served
- xi. Languages spoken
- xii. Target groups served
- xiii. Quality of service provided



- xiv. Supportive services any service that is not AT-related but deemed essential to meet the "whole person" needs of individuals with disabilities
- xv. Appeal denial procedures/process
 - Legislative mandate(s) on the right to receive service
 - Contact person to appeal denial
 - Advocacy and support agencies that can support individuals in their appeal processl
- xvi. I&R linkages to referral source
- xvii. Legislative efforts affecting service delivery

c. Maintaing the Dutabase

This service will be responsible for developing procedures to maintain the quality, accuracy, and timeliness of the National AT I&R 1-800 telephone number database. This will require the implementation of the following actions:

- i. Establish criteria for the inclusion or exclusion of agencies and programs;
- ii. Develop procedures for updating the database on a quarterly basis;
- iii. Develop procedures to determine the accuracy of referrals; and
- iv. Establish assurances that meet liability concerns that administrative procedures have been complied with in providing referral information.

d. Reporting on Scope of Activities: Policy and Planning Functions

The ability to document the scope of activities provided by the AT 1-800 number is a central function of this service. Documentation of activities facilitates the identification of gaps in services and unmet needs and provides aggregate data on the users of the service and the level of effort being requested by consumers. In order to manage this central function, the AT I&R service shall maintain the following information on the users of the 1-800 number:

- Call number and date of call;
- Beginning and ending time of call;
- Demographic information on the caller (i.e., geographic area of origin, geographic area of services needed, age, gender);
- Name, address, and telephone number to be reached;



- Requested information/referral;
- Action taken (i.e., provided information or referral to service, sent materials, provided initial linkage with service, etc.);
- Method of contacting service (e.g., letter, telephone, on-line, etc.);
- Referral source to AT &R 1-800 service (e.g., agency, consumer, Public Service Announcement [PSA], etc.); and
- Future action(s) (i.e., follow-up strategies and their results).

This information must be maintained utilizing the strictest levels of confidentiality. An analysis of this data will be conducted for compiling reports and documenting the use of the service. Only the statistical analysis of this data will be made public. No personal information that may identify a user of this service will be released. The statistical data may be used to aid NIDRR in their development of policies, guiding the delivery of services, target research efforts, and increasing the dissemination of information on available services.

The activities in this area may affect other areas. They are grouped together to emphasize their importance in the delivery of AT information services, which is the reason for developing a National Assistive Technology Information and Program Referral Network. However, incorporating policy and planning activities into the proposed network creates the opportunity to provide information on unmet needs and gaps in services and document the changing information priorities of consumers. It will be the ability of the proposed network to compile empirical data on the impact of AT I&R services that will help to formulate future policy directions to guide the delivery of AT I&R services.

B3: ASSISTIVE TECHNOLOGY SERVICES AND DEVICES EVALUATION PROJECT

<u>ACTIVITY (ies)</u>: Primary distribution for consumers of technology-related information needing evaluation and quality-based information on AT devices or services.

- a. Provide an abstract database of evaluation/research conducted by the contractor. This is to be available through multiple access points.
- b. Develop a single-page abstract of consumer-oriented AT-related topics.
- c. Coordinate distribution of AT evaluation and research field efforts through electronic media.
- d. Develop fact sheets for consumers on how to evaluate AT devices and services.

The proposed approach to implement this area will use a computerized interactive system that can match the information needs of a consumer for technology-related devices to available assistive equipment and the evaluation reports on the device. This approach matches the required types of information to the needs of the consumer of the technology-related devices. The present state of technology allows a computerized system to be designed that would incorporate these components into an interactive information database by using an expert



system. An expert system is composed of computer programs capable of emulating human experience through the use of a knowledge base and inference rules to solve selected kinds of problems. This technology allows functions that require extensive experience and applications to be performed in a uniform manner. The information derived from this database has the potential to provide consumers with information from which they can make decisions related to purchasing, use, and funding of assistive devices.

B4: ASSISTIVE TECHNOLOGY I&R FIELD INITIATED RESEARCH AND INNOVATION PROJECTS

ACTIVITY (ies):

- a. Conduct research on AT I&R "best practices".
- b. Conduct research on strategies to develop and utilize funding streams for AT I&R services as related to "best I&R practices".

Information and program referral is an emerging field that must be nurtured through the sponsorship of research activities that document its impact on the daily lives of individuals. The rapid pace of information development and the advent of technology requires that scientific study be conducted on the types of information and practices that provide consumer access and outreach. In the last 20 years it has been documented that access to information is vital for all individuals to live full and productive lives. This study found that the role of information is equally as crucial in the lives of individuals with disabilities. The time has come to accept the need for information brokers and determine the best methods and practice by which to provide information services. Support for field initiated research in the I&R field will help to document this effort, avoid the duplication of efforts, target funding initiatives, and provide policy direction to take us into the next century.

B5: NATIONAL ASSISTIVE TECHNOLOGY PUBLIC AWARENESS CAMPAIGN

ACTIVITY (ies):

Awareness of the role and availability of assistive technology is the first step toward ensuring that individuals with disabilities have access to technology-related information. Although NIDRR has supported autonomous public awareness initiatives under Part C of Public Law 100-407, this study documented the need to expand this effort on the national level and provide the State-funded projects with technical support for their local efforts.

- a. Develop a national media campaign to promote the visibility and impact of AT (including public service time slots on radio and television).
- b. Formulate a plan and generic media packets to be used as part of the outreach efforts of AT I&R NIDRR-funded projects.
- c. Develop generic media packets and materials to be used by the State-funded projects in promoting their AT projects.



B6: ASSISTIVE TECHNOLOGY INFORMATION AND PROGRAM REFERRAL SERVICES TAXONOMY PROJECT

ACTIVITY (ies):

- a. Develop an AT I&R services taxonomy (classification system).
- b. Develop a thesaurus of common terms to be used in conjunction with the services taxonomy or independently from the taxonomy by practitioners and consumers.
- c. Develop standardized definitions for all terms used in the taxonomy. These definitions must be developed from an interdisciplinary perspective to reflect the diversity of fields working with technology-related information.

Subsequent sections explore the implementation of these centralized components within the framework of a facilitative network organizational arrangement.



Chapter Five

IMPLEMENTATION PLAN

he success of network systems requires a broad base of support among members, effective leadership, and a clearly defined mission. Successful networks facilitate the work of members by building upon their strengths and providing support mechanisms for new initiatives. Connor (1979) cites ten factors for building a successful network. These factors are incorporated into recommendations made to guide the establishment of a national AT I&R network. Seven key factors were taken into consideration in the design of the implementation plan. These factors are:

- 1. Providing effective leadership.
- 2. Building on the strengths of its members.
- 3. Designed to interface with other networks.
- 4. Communication structures across inter-organizational boundaries.
- 5. Provision for conducting an evaluation of its efforts and a willingness to change in light of experience.
- 6. Large base of support across funding sources, consumers, and members of the network.
- 7. All members must be committed to providing support to maintain the effort of the network.

Successful networks facilitate the work of members by building upon their strengths.

A. Assistive Technology Information and Program Referral Coordinating Institute

<u>Purpose</u>: The purpose of the Assistive Technology Information and Program Referral Coordinating Institute will be to facilitate a coordinated approach for the delivery of AT I&R services in support of the mission of the National Assistive Technology Information and Program Referral Network as described in Sections I and II.

Eligible Applicants: Institutions of higher education in collaboration with non-profit and for-profit entities with the mission of providing services for individuals with disabilities are eligible to apply for assistance under this component.

<u>Functions</u>: The purpose of the Assistive Technology Information and Program Referral Coordinating Institute (hereafter known as the "AT I&R Coordinating Institute") will be carried out through the following functions:



- (a.) To provide training for AT I&R brokers in the following areas:
- 1. Provide training and technical support in the provision of AT I&R services.
- 2. Provide training in operating an on-line AT I&R system.
- 3. Provide training on how to establish and operate an AT I&R service
- 4. Develop and disseminate training modules on the delivery of AT I&R services for information brokers to help bridge research and practice.
- 5. To disseminate information on I&R field initiated research and innovation projects.
- (b.) To provide technical support for members of the National Assistive Technology Information and Program Referral Network in the following areas:
- 1. Designing an AT I&R database structure.
- 2. Providing guidance with hardware/software selection through an annual conference and fact sheets listing available I&R software and hardware.
- 3. To support AT I&R providers and the assistive technology field by identifying and disseminating innovative resources.
- (c.) To promote a coordinated approach for the delivery of AT I&R service delivery:
- 1. Establish a committee to be known as the Assistive Technology Information and rogram Referral Advisory Committee (hereafter known as the "Advisory Committee").
- 2. The Advisory Committee shall be composed, at minimum, of the Program Directors of all six NIDRR-funded centralized activities of the National Assistive Technology Information and Program Referral Network, representatives of NIDRR Utilization and Dissemination Projects, consumers of AT I&R services, consumer advocacy organizations, members of the National Assistive Technology Information and Program Referral Network, a NIDRR representative, and manufacturers of AT devices.
- 3. The Advisory Committee will be convened by the AT I&R Coordinating Institute twice a year to review all the activities of the six centralized components and the current state of AT I&R practice and to formulate collaborative agreements for these activities.
- 4. It will be the responsibility of the staff of the AT I&R Coordinating Institute to facilitate the meetings of the Advisory Committee and provide quarterly reports to all its members on the status of projects and new and upcoming initiatives.



- (d.) To aid in the development of a coordinated approach for the delivery of AT I&R services:
- 1. Assist in developing an AT I&R services taxonomy (classification system), definition of terms, and thesaurus.
- 2. Assist in developing an evaluation network for local and regional AT I&R systems.
- 3. Assist in developing ATI&R standards for data compatibility and data interchange at all levels of information distribution.
- 4. Assist in developing standards to guide AT information and referral practitioners.
- 5. Promote interagency and multidisciplinary cooperation among all members of the network.

Funding:

- (a.) The AT I&R Coordinating Institute should be funded by a five-year grant to facilitate a coordinated approach for the delivery of AT I&R services in support of the mission of the National Assistive Technology Information and Program Referral Network. Eligible applicants must submit a five-year work plan on the scope of activities to be completed through the grant.
- (b.) The grant shall be in an amount of no less than \$350,000 and no more than \$550,00 for each grant year. The amount to be awarded is to be calculated based on the scope of the activities and not on the lowest bid to complete the described activities.
- (c.) This grant should be awarded through competitive bids, using a Request for Proposals format.
- B. 1-800 Telephone Number: Assistive Technology Information and Program Referral System

<u>Purpose</u>: The general purpose of the 1-800 Telephone Number Assistive Technology Information and Program Referral System will be to serve consumers as a referral source to available AT I&R providers and provide technology-related information at the national level and information not located by the caller through local, state, or regional resources. The service would complement existing AT I&R systems by providing referrals and linkages to these providers.

Eligible Applicants: Non-profit agencies such as institutions of higher education and consumer focus agencies with a national perspective are eligible to apply for this component. Applicants must demonstrate an extensive work history in providing I&R services at the local, regional, and national levels.



<u>Functions</u>: The purpose of the 1-800 Telephone Number Assistive Technology Information and Program Referral System (hereafter known as the "AT I&R 1-800 Number System") will be carried out through the following functions:

- (a.) To provide a national AT I&R 1-800 Number System that maintains and disseminates the following types of information:
- 1. Information on AT I&R services available throughout the United States.
- 2. Information on federal legislation affecting AT I&R services.
- 3. Information on technology-related services and devices.
- 4. Information on funding sources (i.e., general and at community levels for technology-related services and devices).
- 5. Information on training and program materials affecting the dissemination and delivery of information services.
- 6. Information on AT I&R field initiated research and innovation projects.
- (b.) The information disseminated through the AT I&R 1-800 Number System is to be accessible on a national level through multiple-access and alternate formats to include, but not be restricted to, an on-line database, a 1-800 telephone number, printed materials, and fact sheets. Access must be assured to traditionally underserved consumers in the establishment of alternative formats.
- (c.) The AT I&R I-800 Number System is to maintain a computerized database for dissemination of the following types of information on a national level for technology-related agencies, programs, and services:
- 1. Agency and program general information:
 - Agency and program name(s) (common name and acronym).
 - Mailing address, city, county, state, and ZIP code.
 - Local address, city, county, state, and ZIP code.
 - Telephone, toll-free, TDD, and fax number(s).
 - Name of Agency/Program Director, Referral, and Grievance Contact Person(s).
 - Accessibility of service site.
- 2. Description of the service or device:
 - Name of service or device.
 - Description of service or device.
- 3. How to apply for services, the referral process, and documents required.
- 4. Types of disabilities/conditions served.
- 5. Cost of service/device:
 - Fee schedule.
 - Associated costs.



- 6. Funding for service/device:
 - Type of payment accepted (i.e., insurance, credit card, check, loan, lease, and others).
 - Availability of financial assistance.
 - Funding legislation.
- 7. Eligibility requirements and length of time on a waiting list.
- 8. Ages and genders served.
- 9. Hours of operation and time zone.
- 10. Geographic area served.
- 11. Languages spoken.
- 12. Target groups.
- 13. Quality of service provided.
- 14. Supportive services: any service that is not AT-related but deemed essential to meet the "whole person" needs of individuals with disabilities.
- 15. Appeal denial procedures/process:
 - Legislative mandate(s) on the right to receive service.
 - Contact person to appeal denial.
 - Advocacy and support agencies that can support individuals in their appeal process.
- 16. I&R linkages to referral source.
- 17. Legislative efforts affecting service delivery.
- (d.) The AT I&R 1-800 Number System is to ensure the quality, accuracy, and timeliness of the computerized database by developing and implementing procedures in the following areas:
- 1. Establish criteria for the inclusion or exclusion of agencies and programs.
- 2. Develop procedures to update the database on a regular basis.
- 3. Develop procedures for verifying the database on a six-month basis.
- 4. Develop procedures to determine the accuracy of referrals.
- 5. Establish procedures to meet liability concerns that administrative procedures have been complied with in the provision of I&R services.



- 6. A review of all established procedures is to be coordinated through the Advisory Committee or the AT I&R Coordinating Institute.
- (e.) The AT I&R 1-800 Number System is to provide NIDRR a quarterly report on their scope of activities. The report to NIDRR will consist of aggregate statistical data which document the use of the service. No personal information that may identify a user of this service will be released. The documentation of activities is to be used to facilitate the identification of gaps in services and unmet needs and provide aggregate data on the users of the service and the level of effort being requested by consumers. In order to manage this central function, the AT I&R 1-800 Number System shall maintain, at minimum, the following information:
- 1. Call number and date of call.
- 2. Beginning and ending time of call.
- 3. Demographic information on caller (i.e., geographic area of origin, geographic area of services needed, age, gender).
- 4. Name, address, and telephone number to be reached.
- 5. Requested information/referral.
- 6. Action taken (i.e., information provided or referral to service, materials sent, initial linkage with service provided, etc.).
- 7. Method of contacting service (e.g., letter, telephone, on-line, etc.).
- 8. Referral source to ATI&R 1-800 Number System (e.g., agency, consumers, PSA, etc.).
- 9. Future action(s) (i.e., follow-up strategies and their results).
- 10. Caller(s)' problems accessing existing services.
- (f.) The program director of the AT I&R 1-800 Number System is to serve as a participating member of the Advisory Committee of the AT I&R Coordinating Institute. Participation in the Advisory Committee will serve to facilitate a coordinated approach for the delivery of AT I&R services.
- (g.) The staffing of the AT I&R 1-800 Number System must reflect both a high degree of sensitivity for consumers and the interdisciplinary nature of technology-related information.

Funding:

(a.) The AT I&R 1-800 Number System should be funded by a three-year grant to provide a national technology-related I&R service. The grantee must submit a three-year work plan on the scope of the activities undertaken by the grant.



- (b.) The grant shall be in an amount of no less than \$250,000 and no more than \$400,00 for each grant year. The amount to be awarded is to be calculated based on the scope of the activities and not on the lowest amount bid to complete the activities.
- (c.) This grant should be awarded through competitive bids, using a Request for Proposals format.

C. Assistive Technology Services and Devices Evaluation Project

<u>Purpose</u>: The general purpose of the Assistive Technology Services and Devices Evaluation Project is to provide consumers with evaluative and quality-based information on available technology-related services and devices.

Eligible Applicants: Non-profit organizations with proven track records of conducting research and dissemination of research findings on AT devices, and responsive to the technology-related needs of individuals with disabilities are eligible to apply for assistance under this component. Non-profit organizations operating under the auspices of a for-profit parent organization must provide assurances that the staff of this project is free of any potential conflict of interest situations with for-profit entities that might compromise the purpose of the project. Such assurances can include a listing of all the technology-related for-profit activities of the parent organization and the procedures initiated to avoid the potential for conflict of interest between this project and the parent organization.

<u>Functions</u>: The purpose of the Assistive Technology Services and Devices Evaluation Project (hereafter known as the "AT Evaluation Project") will be carried out through the following functions:

- (a.) To develop criteria for the evaluation of technology-related devices and services.
- (b.) To conduct independent evaluations of technology-related services.
- (c.) To develop an electronic information database of AT evaluation and research efforts on existing technology-related devices (hereafter known as the "AT Evaluation and Research Database"). This electronic database must be interactive in nature to allow for matching the technology-related information needs of the consumer with known devices, funding restrictions, and evaluation criteria.
- (d.) To disseminate the AT Evaluation and Research Database to existing NIDRR Information Utilization projects.
- (e.) To develop and disseminate single-page abstracts of consumer-oriented AT-related topics.
- (f.) To develop and disseminate fact sheets for consumers on how to evaluate AT devices and services.



(g.) The Project Director is to serve as a participating member of the Advisory Committee of the AT I&R Coordinating Institute. Participating in this Advisory Committee will serve to facilitate a coordinated approach for the delivery of AT I&R services.

Funding:

- (a.) The AT Evaluation Project should be funded by a three-year grant to facilitate the work of the project.
- (b.) The grant shall be in the amount of no less than \$250,000 and no more than \$400,000 for each grant year. The amount to be awarded is to be calculated based on the scope of activities to be completed in each fiscal year. First-year funding might reflect a higher level of funding over subsequent years to reflect the costs associated with the development of this project.
- (c.) This grant should be awarded through competitive bids, using a Request for Proposals format.
- D. Assistive Technology I&R Field Initiated Research and Innovation Projects

<u>Purpose</u>: To document the impact of information services on meeting the technology-related needs of individuals and determine the "best practices" for delivering AT I&R services.

Eligible Applicants: Non-profit or for-profit entities demonstrating the capacity to conduct field initiated research and innovation projects are eligible to apply for assistance under this component.

Functions: The purpose of the Assistive Technology I&R Field Initiated Research and Innovation Projects (hereafter known as the "AT I&R Field Initiated Projects") may be carried out through the following activities:

- (a.) Field initiated research on the "best practices" to deliver AT I&R services.
- (b.) Field initiated research on strategies to develop and utilize funding streams for Assistive Technology I&R services as they relate to "best practices".
- (c.) Field initiated research on the "best practices" to deliver AT I&R services to traditional underserved consumers.

Funding:

(a.) The AT Field Initiated Projects should be funded by a one-year grant, contract, or cooperative agreement with non-profit or for-profit entities.



(b.) Funding shall not exceed \$50,000 for each project, with a minimum total allocation of \$200,000 for four projects on a yearly basis.

E. National Assistive Technology Public Awareness Campaign

<u>Purpose</u>: The National Assistive Technology Public Awareness Campaign has two complementary purposes. The first is to bring to individuals with disabilities the message of what assistive technology is and that technology-related products have a place in their daily lives. The second purpose is to provide information about where to turn for help, particularly how to reach local technology-related services, and how to access the AT I&R Network.

Eligible Applicants: Non-profit or for-profit organizations with a proven track record of developing national public awareness campaigns and an organization that is sensitive to the needs of individuals with disabilities are eligible to apply for assistance under this component.

<u>Functions</u>: The purpose of the National Assistive Technology Public Awareness Campaign (hereafter known as the "AT Public Awareness Campaign") will be carried out through the following functions:

- (a.) Develop a national media campaign to promote the visibility and impact of assistive technology (including public service time slots on radio and television).
- (b.) Formulate a plan and generic media packets to be used as part of the outreach efforts of AT I&R activities of NIDRR-funded projects.
- (c.) Develop and distribute generic media packets and materials to be used by the assistive technology State-funded projects to promote their AT projects.
- (d.) All written materials must be developed with sensitivity for the cultural diversity and characteristics of consumers of technology-related information. At minimum, all materials must be developed with oversight provided by a nationally representative committee of technology-related information consumers.
- (e.) The Project Director of the AT Public Awareness Campaign is to serve as a participating member of the Advisory Committee of the AT I&R Coordinating Institute. Participation in the Advisory Committee will serve to facilitate a coordinated approach for the delivery of AT I&R services.

Funding:

- (a.) The AT Public Awareness Campaign should be funded by an 18-month contract or cooperative agreement.
- (b.) Funding shall be in the amount of no less than \$750,000 and no more than \$1,500,000 for the period of the contract or cooperative agreement.



F. Assistive Technology Information and Program Referral Service Taxonomy Project

<u>Purpose</u>: The purpose of the Assistive Technology Information and Program Referral Service Taxonomy Project is to develop a common language framework for the delivery of AT I&R services.

Eligible Applicants: Non-profit organizations with a proven track record of providing I&R services, extensive knowledge of the development of taxonomy systems, and experience in collaborating to develop interdisciplinary initiatives are eligible to apply for assistance under this component. Applicants must submit cooperative agreements with other agencies/organizations that reflect a collaborative interdisciplinary approach in accomplishing the purpose of the project. The approach must build upon existing classification systems for the delivery of AT I&R services.

<u>Functions</u>: The purpose of the Assistive Technology Information and Program Referral Service Taxonomy Project (hereafter known as the "AT I&R Taxonomy Project") will be carried out through 999the following functions:

- (a.) Develop an assistive technology service taxonomy for delivering AT I&R services.
- (b.) Develop a thesaurus of common terms to be used in conjunction with the service taxonomy or independently by practitioners and consumers.
- (c.) Develop standardized definitions for all terms used in the taxonomy. The definitions must reflect the diversity of fields providing technology-related information.
- (d.) All products developed by this project must be available in both written and electronic media.
- (e.) The Project Director is to serve as a participating member of the Advisory Committee of the AT I&R Coordinating Institute.

Funding:

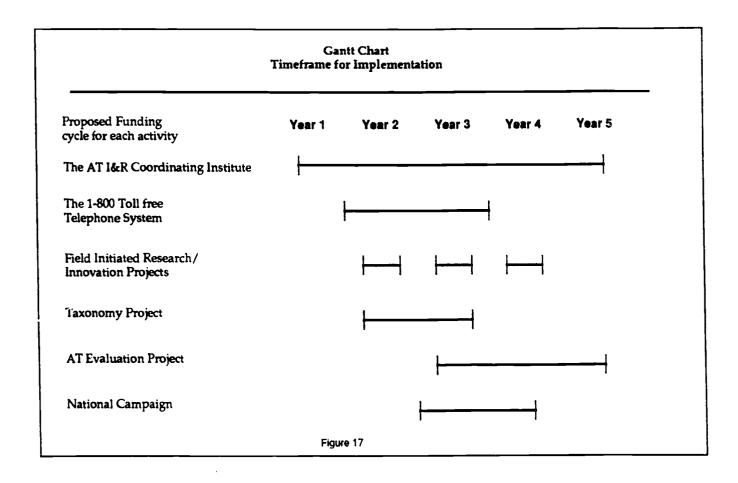
- (a.) The AT I&R Taxonomy Project should be funded by an 18-month contract to complete the work of the project.
- (b.) The contract shall be in the amount of no less than \$150,000 and no more than \$200,000. The amount to be awarded is to be calculated based on the scope of the activities.
- (c.) This contract should be awarded through competitive bids, using a Request for Proposals format.



A thorough review of U.S. Department of Education criteria for designating organizations as eligible to respond to a Request for Proposals (RFP) formed the basis for the recommendations throughout the implementation plan. The research staff reviewed the organizational staffing and funding streams of 20 funded projects and activities with similar types of functions. This review helped formulate recommendations for eligible applicants and funding categories. The recommended funding levels consider the salaries and costs associated with different geographic regions. Due to these factors, the research staff strongly felt that it was impossible to assign a staffing level for any of the proposed components because this would severely limit the competitive bid process and restrict components to those levels.

IMPLEMENTATION PERIOD

A staggered timetable is proposed for implementation of a national AT I&R network. The study findings suggest it is essential to address the disparity in delivery of AT I&R services. A five-year period is recommended for implementing all of the components. This period allows for a review of each activity and allows them to build upon each other in creating the National Assistive Technology Information and Program Referral Network. Figure 17 illustrates the proposed approach for implementing the centralized components of the network.



Year One: Funded Components

Facilitating a coordinated approach to the delivery of AT I&R is at the heart of establishing a national AT I&R network. To meet this goal requires that a unit be established to guide the process. It is proposed that the AT I&R Coordinating Institute be funded before other centralized functions. A five-year funding cycle is recommended for this activity to ensure that the necessary mechanisms are established, field-tested, evaluated, and assimilated by network members. Research on the utilization of new services suggests that a five-year cycle is required for individuals to incorporate new ideas (Rossi and Freeman, 1988). It is believed that the functions outlined for this activity will require five years to be incorporated into the AT I&R service delivery system.

Year Two: Funded Components

Three components are proposed for funding in the second year (i.e., the 1-800 Number System, the AT I&R Taxonomy Project, and the AT I&R Field Initiated Projects). An atmosphere of collaboration is essential to the success of these components. Each activity relies on the Advisory Committee to help coordinate their work. Establishing the 1-800 Number System must occur simultaneously with developing the AT I&R Taxonomy Project. The AT I&R Field Initiated Projects can test the impact of the first year of the AT I&R Coordinating Institute on the delivery of AT I&R services and provide input for new components.

Year Three: Funded Components

Two components are proposed for funding in the third year (i.e., the AT Public Awareness Campaign and the AT Evaluation Project). The activities developed in the first two years of the funding cycle are deemed essential to the success of these components. The components are linkages for meeting the information needs of consumers of AT I&R services. The framework developed for the delivery of AT I&R services must be in place before funding these projects.

Years Four and Five: Funded Components

Continued funding for four of the six components is recommended for the fourth year (i.e., the AT I&R Coordinating Institute, the ATechnology Evaluation Project, and the 1-800 Number System, and the AT Public Awareness Campaign). In the fifth year the AT I&R Coordinating Institute and the AT Evaluation Project will receive continued funding. An evaluation of the six centralized components will be used to make future recommendations beyond this five-year funding cycle. It is the contractor's opinion that this evaluation is essential in measuring the impact of these components on the delivery of AT I&R services. It is also essential in determining the information needs of consumers. Failure to do this may result in the institutionalization of these components without an analysis of the impact and changing needs of consumers.



APPENDIX A

REGIONAL FOCUS GROUP PARTICIPANTS

&

FOCUS GROUP MODERATOR'S GUIDE



SOUTHEASTERN REGIONAL FOCUS GROUP August 28, 1991

Barbara Edwards
Bureau of Education for Exceptional

Children
Tallahassee, FL

Clarice Eichelberger Developmental Disabilities Council Baton Rouge, LA

Shelly Kaplan
The SMART Exchange
Atlanta, GA

Paul Knight
SC Vocational Rehabilitation Department
West Columbia, SC

Joy Kniskern
Department of Human Resources
Atlanta, GA

Anthony Langton
SC Vocational Rehabilitation Department
West Columbia, SC

John Schweitzer Louisiana Tech University Ruston, LA

> Jim Toler Georgia Tech Atlanta, GA

Larry Trachtman
North Carolina Assistive Technology
Project
Raleigh, NC

Terry Ward
Division of Vocational Rehabilitation
Tallahassee, FL

Denise Wiles
University of South Carolina
Columbia, SC

Naama Zahavi-Ely Virginia Assistive Technology System Richmond, VA



NORTHEASTERN REGIONAL FOCUS GROUP September 4, 1991

Elizabeth Anderson
Research and Training Center for Access to
Rehabilitation and Economic Opportunity
Washington, DC

Mary Brady
Maryland Technical Assistance Program
Baltimore, MD

Jay Brill

Maryland Technical Assistance Program

Baltimore, MD

Margaret Burley
Ohio Coalition for the Education of
Handicapped Children
Columbus, OH

Ricardo Ceme
Connecticut Rehabilitation Engineering
Center
Glastonbury, CT

Daly Enstrom

Related Services and Communication

Resource Center

Trenton, NJ

Susan Garber
Center for Technology and Human
Disabilities
Baltimore, MD

Richard Horne NICHCY McLean, VA Peter Johnke Vermont Center for Independent Living Montpelier, VT

> George Jones New England INDEX Waltham, MA

> > Linda McQuistion Columbus, OH

Richard Mirisola American Foundation for the Blind New York, NY

Mary Ann O'Toole

Massachusetts Assistive Technology
Program
Boston, MA

Janie Scott
Clearinghouse for Rehabilitation &
Technology Information
Baltimore, MD

Janice Williams
Special Initiative of DC Rehabilitation
Services Administration
Washington, DC



MIDWESTERN REGIONAL FOCUS GROUP September 6, 1991

Sid Cook
Goodwill Center for Independent Living
Grand Island, NE

Roger Levy
Texas Rehabilitation Commission
Austin, TX

Teri Dederer

Department of Rehabilitation Services

Springfield, IL

Roger McCarty
Illinois Assistive Technology Project
Springfield, IL

Lyle Drieling
Nebraska Diagnostic Resource Center
Cozad, NE

Michelle Meidl ATTAIN Project Indianapolis, IN

Joe Ferrara
North Dakota Center for Disabilities
Minot, ND

Jaryl Perkins Department of Social Services Topeka, KS

Amy Hanna Iowa City, IA Diane Price
Division of Rehabilitation Services
Salt Lake City, UT

Roger Hoffmann Iowa City, IA

George Saiki
Office of Vocational Rehabilitation
Bismarck, ND

Christy Horn
University of Nebraska at Lincoln
Lincoln, NE

Mark Schultz Assistive Technology Tincton, NE

Chuck Juhn
Utah Assistive Technology Program
Logan, UT

Rick Sterling

Dakota State University

Madison, SD

Troy Justesen
OPTIONS for Independence
Logan, UT

John Leslie
United Cerebral Palsy Research Foundation
Wichita. KS



WESTERN REGIONAL FOCUS GROUP September 30, 1991

John Abbruscato
DeAnza College
Cupertino, CA

Alice Nemon
San Francisco State University
San Francisco, CA

Bruce Barney Center for Independent Living Berkeley, CA Peter Pfaelzer
San Francisco State University
San Francisco, CA

Carl Brown
DeAnza College
Cupertino, CA

Priscilla Sanderson Vocational Rehabilitation Flagstaff, AZ

Bill Crandall
Smith-Kettlewell Eye Research Institution
San Francisco, CA

Patricia A. Sefton Nevada Technology Center Reno, NV

William Cutler Self Help for the Hard of Hearing Palo Alto, CA Susan Sterne
Deaf & Disabled Telecommunications
Program
Oakland, CA

John Darby Hearing Society for the Bay Area, Inc. San Francisco, CA

Jeff Symons Department of Rehabilitation - CARE Sacramento, CA

Frank DeRuyter
Rancho Los Amigos Medical Center
Downey, CA

Lisa Wahl

DCCG - Technology Resources for People

With Disabilities

Berkeley, CA

Alexandra Enders
University of Montana
Missoula, MT

John Webb Oregon State Library Salem, OR

James Fruchterman Arkenstone, Inc. Sunnyvale, CA

ASSISTIVE TECHNOLOGY FEASIBILITY STUDY CONSUMER REGIONAL FOCUS GROUP

MODERATOR'S GUIDE

CENTER FOR DEVELOPMENTAL DISABILITIES
UNIVERSITY OF SOUTH CAROLINA
COLUMBIA, SC 29208
803-777-8109

DEVELOPED BY ANA LOPEZ-DE FEDE, PROJECT DIRECTOR
Under a contract between NIDRR, US Department of Education and the University of South Carolina

7/17/91

ERIC Full Bast Provided by ERIC

ASSISTIVE TECHNOLOGY FEASIBILITY STUDY CONSUMER REGIONAL FOCUS GROUP

MODERATOR'S GUIDE

A. CONSUMER REGIONAL FOCUS GROUP PROPOSED FORMAT

Introductory	Remarks - This morning w	e will be talking about your infor that could assist you with daily a	mation and referral activities. My name
is	and this is n to talking to and hearing viduals with disabilities to	r from individuals across the cou obtain information on assistive	and intry about the best

[Pause]

Assistive Technology services or devices can be any service or equipment that helps to increase, maintain, or improve the daily lives of individuals with disabilities.

[Pause. Ask for any questions about the definition and provide some examples of assistive technology services and devices.]

We are asking you to help us today by sharing with us some of your experiences and your thoughts on the best way for you to obtain information and referrals for assistive technology services and/or devices.



AGENDA

- I. Introduction of Participants Name and two things they would like to share about themselves or their disability. [Moderator models the introduction, placing emphasis on self-disclosure.]
- II. Introduction of the Agenda
 - a. Review Agenda
 - b. Roles and Responsibilities of Participants [See Attached: Group Member Roles]
 - c. Questions
- III. Availability of Information [Brainstorm and Discussion]
 - a. In the past year, what type of information related to assistive technology services and devices have you tried to obtain?
 - b. When you've needed information about assistive technology services or devices, where have you turned to get the information?
- IV. Information and Referral Needs [Brainstorm and Discussion]
 - a. What type of information and referral service could best meet your needs? (Explore local, regional, and national options.)
 - b. What would this service need to provide in order to meet your needs? [Explore type(s) of information.]
 - c. What is the best way for people to be able to access and use information about assistive technology services and devices?
 - d. What is the best way to let individuals know how to obtain information about assistive technology services and devices?
- V. Ideal Assistive Technology Information and Referral Service
 - a. If you could help design a national network (services that could interact with one another across state lines and on a national level), what would this national network do?
 - b. How would a national network differ from local or regional information and referral services or programs?
 - c. What advantages could a national network offer you?
 - d. What essential components (parts) must a national network have to meet the needs of consumers?
- VI. Closing Group [Summarize key responses and seek clarity for unclear items]
 - a. Thank Participants
 - b. Distribute Participant Request for Summary Consumer Report Form
 - c. Next Steps
- Note: Some participants may not be ready to end the group. If this occurs, informally continue the discussion and include these "side discussions" as part of the report for the session.



B. FOCUS GROUP PARTICIPANTS

I. Selection

The selection of individuals for participation in the consumer regional focus groups will be based on the following criteria:

- a. Groups that are under-represented in the surveyed population.
- b. Groups that are not represented in the survey population. All participants must be individuals who have some knowledge of assistive technology and information and referral services.
- c. Attempts will be made to hold homogeneous groups comprised of individuals meeting the same selection criteria, e.g., age, type of disability, etc.

NOTE: Individuals lacking basic knowledge of these two areas can be best included in the study through conducting individual interviews. The use of individual interviews can provide the mechanism to both solicit their opinions and provide basic knowledge in these two areas.

II. Invitation To Participate

Invitations to participate in the consumer groups may be done through a contact in a specific agency and followed by a confirmed invitation from the hosting subcontractor. A list of participants will be provided to the University of South Carolina by RESNA, Inc., for distribution to the sub-contractors. RESNA, Inc., will work in conjunction with USC to develop the list of participants based on the selection criteria. (See Attached Potential List of Regional Focus Group Participants.)

III. Group Size

The recommended size for each meeting group is a maximum of ten. This size is recommended to ensure the participation of all individuals in the proposed discussion format.

C. MEETING LOGISTICS

I. Site of Group Meeting

The site of the consumer groups will vary based on two variables: 1) co-facilitation with the scheduled Service Provider Regional Focus Groups and 2) the need to hold focus groups that include under-represented and non-represented groups of consumers.

The site of the group meetings held in conjunction with scheduled regional focus groups will be determined by the University of South Carolina. However, all other group meeting sites will be selected by RESNA, the sub-contractor responsible for the Consumer Perspective Phase of the study.



II. Meeting Format

The meeting format will be a small group format that enhances group interaction through a structured agenda, open-ended question format, and the use of process recording that will serve as the group memory. The room arrangement will be determined by the subcontractor. It is recommended that the subcontractor take into consideration the following variables in selecting the room arrangement: a) maximum group interaction with the ability for the facilitator to walk in and out of the group, b) the arrangement facing away from the door to allow for ease of entrance and exit by the participants, and c) the location a wall suitable for taping a group memory.

The group session will be facilitated by a group leader who manages the meeting process. This will require the group leader to possess the following characteristics: a) neutral facilitator of the group, b) does not evaluate or contribute ideas, c) focuses the energy of group on common agenda tasks, d) protects all group participants and their ideas from individual attack, e) encourages the participation of all group members, and f) coordinates pre- and post-meeting logistics.

The group leader can employ the following specific techniques to help them accomplish the agenda: a) clearly define the role of the group leader versus the participants, b) get agreement on the agenda and the meeting group processing the introduction of the agenda; c) restate questions for the group; d) be positive: compliment the group on progress; e) limit the comments of the group leader to process comments, i.e., how to conduct the meeting, and not content comments, i.e., what the meeting is all about; f) support recording key points as group memory for all participants to view; g) do not be afraid to make mistakes and to reorder the egenda; and h) stick to designated time frame for the meeting.

Note: For further elaboration on these techniques review the book <u>The Interaction Method:</u>
How To Make Meetings Work by Michael Doyle and David Straus (1976).



GROUP PARTICIPANTS

A. ROLES AND RESPONSIBILITIES

- 1. Keep the group leader neutral and out of the content discussion.
- 2. Make sure your ideas are recorded accurately in the group memory.
- 3. Focus your energy on the content of the problem.

B. GROUND RULES FOR THE GROUP

- 1. Respect and listen to other individuals.
- 2. Try to keep an open mind.
- 3. Don't be prematurely negative.
- 4. Every opinion is valid and important.
- 5. There is no such thing as a silly question.
- 6. Don't cut other people off or put words in their mouths.

Note: Allow the group to add their own items to this list.



ASSISTIVE TECHNOLOGY FEASIBILITY STUDY SERVICE PROVIDER REGIONAL FOCUS GROUP

MODERATOR'S GUIDE

CENTER FOR DEVELOPMENTAL DISABILITIES UNIVERSITY OF SOUTH CAROLINA COLUMBIA, SC 29208 803-777-8109

DEVELOPED BY ANA LOPEZ-DE FEDE, PROJECT DIRECTOR
Under a contract between NIDRR, US Department of Education and the University of South Carolina

7/17/91

ASSISTIVE TECHNOLOGY FEASIBILITY STUDY SERVICE PROVIDER REGIONAL FOCUS GROUP

MODERATOR'S GUIDE

A. REGIONAL FOCUS GROUP PROPOSED FORMAT

Introductory Remarks: Today we will be aski	ng for your thoughts on the key feasibility and
desirability issues impacting the formation of	a National Assistive Technology Information
and Program Referral Network. My name is	and this is
I work with as a sub-	contractor of the University of South Carolina,
who is conducting a national study to d	etermine the feasibility and desirability of
establishing a National Assistive Technology	Information and Program Referral Network.
As part of this study, the University of South	Carolina surveyed five hundred and forty-one
(541) organizations that provide assistive tech	inology information and referral services. The
preliminary findings of this survey will be pr	esented to you today. We will be asking you to
respond to these initial findings by sharin	g your concerns and ideas on the presented
	l today will be incorporated into the final
recommendations of the study.	

[Pause]

For purposes of this study the following definitions were used:

- 1. Assistive Technology services or devices can be any service or equipment that helps to increase, maintain, or improve the daily lives of individuals with disabilities.
- 2. Information and referral service refers to any service that provides information that helps individuals find assistive technology service(s), activities, devices, or advice on needed services.

[Pause. Ask for any questions about the definitions and provide some examples of assistive technology services and devices from the survey protocol.]

In responding to the preliminary findings, we are asking you to comment using your experiences on the ways individuals obtain information and referrals for assistive technology services or devices. Your comments should reflect both your immediate concern to the preliminary findings and future course of actions that could meet those concerns. Our interest in holding these regional focus groups is to ensure maximum exploration of issues that can impact on the feasibility and desirability of establishing a National Assistive Technology Information and Program Referral Network. To help us begin this discussion, packets of the overhead transparencies covering the preliminary findings have been prepared for you. Please look at the table and make sure that each of you has a packet of information with your name.

[Pause. Make sure that every person in the room has a prepared packet.]



AGENDA

- I. Introduction of Participants Name and two things they would like to share about themselves and the meeting outcome. [Group Leader models the introduction, placing emphasis on self-disclosure. Introduce the Group Memory Format by recording the individual expectations.]
- II. Introduction of the Agenda
 - a. Review Agenda
 - b. Role and Responsibilities of Participants
 [See Attached: Group Member Roles. This can be utilized as chart to introduce the roles and expectations of the participants.]
 - c. Questions
- III. Present Study Preliminary Findings [Overhead Transparencies]
- IV. Availability of Information [Brainstorm and Discussion]
 [Note: This section will utilize the data from the preliminary study.]
- V. Information and Referral Needs [Brainstorm and Discussion]
 [Note: This section will utilize the data from the preliminary study with emphasis on local versus regional versus national needs.]
- VI. Ideal Assistive Technology Information and Referral Service
 - a. If you could help design a national network (services that could interact with one another across state lines and on a national level), what would this national network do?
 - b. How would a national network differ from local or regional information and referral services or programs?
 - c. What advantages could a national network offer you?
 - d. What essential components (parts) must a national network have to meet the needs of consumers?
- VI. Closing Group [Summarize key responses and seek clarity for unclear items]
 - a. Thank Participants
 - b. Distribute Participant Request for Feasibility Study Executive Summary Form
 - c. Next Steps
- Note: Some participants may not be ready to end the group. If this occurs, informally continue the discussion and include these "side discussions" as part of the report for the session.



B. FOCUS GROUP PARTICIPANTS

I. Selection

The selection of individuals for participation in the regional focus groups will be based on the following criteria:

- a. Individuals that are under-represented in the surveyed population.
- b. Individuals that are not represented in the surveyed population. All participants must be individuals who have some knowledge of assistive technology and information and referral services.
- c. Attempts will be made to hold homogeneous groups comprised of individuals meeting the same selection criteria.

Note: Individuals lacking basic knowledge of these two areas can be best included in the study through conducting individual interviews. The use of individual interviews can provide the mechanism to both solicit their opinions and provide basic knowledge in these two areas.

II. Invitation To Participate

Invitations to participate in the regional focus groups may be done through a contact in a specific agency and followed by a confirmed invitation from the hosting subcontractor. A list of participants will be provided to the subcontractor by the University of South Carolina. The subcontractor may add to the initial list of participants by working in conjunction with USC to expand the list of participants based on the selection criteria. (See Attached Potential List of Regional Focus Group Participants.)

III. Group Size

The recommended size for each meeting group is a maximum of twenty-five. This size is recommended to ensure the participation of all individuals in the proposed discussion format.

C. MEETING LOGISTICS

I. Site of Group Meeting

The sites of the regional focus groups will vary based on two variables. 1) coordination of sites and dates with the University of South Carolina to ensure the logistics of both the Consumer and Service Provider Regional Focus Groups and 2) the University of South Carolina will provide tentative suggested site arrangements and dates for these meetings. However, it is the primary responsibility of the subcontractor to finalize all arrangements. [Refer to Sub-contract for details on this section.]



II. Meeting Format

The meeting format will be a small group format that enhances group interaction through a structured agenda, open-ended question format, and the use of process recording that will serve as the group memory. The room arrangement will be determined by the subcontractor. It is recommended that the subcontractor take into consideration the following variables in selecting the room arrangement: a) maximum group interaction with the ability for the group facilitator to walk in and out of the group, b) the arrangement facing away from the door to allow for ease of entrance and exit by the participants, and c) the location of a wall suitable for taping a group memory.

The group session will be facilitated by a group leader who manages the meeting process. This will require the group leader to possess the following characteristics: a) neutral facilitator of the group, b) does not evaluate or contribute ideas, c) focuses the energy of group on common agenda tasks, d) protects all group participants and their ideas from individual attack, e) encourages the participation of all group members, and f) coordinates pre- and post-meeting logistics.

The group leader can employ the following specific techniques to help them accomplish the agenda: a) clearly define the role of the group leader versus the participants; b) get agreement on the agenda and the meeting group processing the introduction of the agenda; c) restate questions for the group; d) be positive: compliment the group on the progress; e) limit the comments of the group leader to process comments, i.e., how to conduct the meeting, and not content comments, i.e., what the meeting is all about; f) support recording key points as group memory for all participants to view; g) do not be afraid to make mistakes and to reorder the agenda; and h) stick to designated time frame for the meeting.

Note: For further elaboration on these techniques review the book <u>The Interaction</u> Method: How To Make Meetings Work by Michael Doyle and David Straus (1976).



GROUP PARTICIPANTS

A. ROLES AND RESPONSIBILITIES

- 1. Keep the group leader neutral and out of the content discussion.
- 2. Make sure your ideas are recorded accurately in the group memory.
- 3. Focus your energy on the content of the problem.

B. GROUND RULES FOR THE GROUP

- 1. Respect and listen to other individuals.
- 2. Try to keep an open mind.
- 3. Don't be prematurely negative.
- 4. Every opinion is valid and important.
- 5. There is no such thing as a silly question.
- 6. Don't cut other people off or put words in their mouths.

Note: Allow the group to add their own items to this list.



APPENDIX B

SURVEY INSTRUMENT PROTOCOLS



Assistive Technology I&R Feasibility Study
Division of Information Technology CD
Benson Building, First Floor
University of South Caroline
Columbia, SC 29208

First Class Mail U.S. Postage Paid Permit #766 Columbia, SC

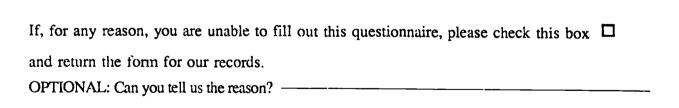
ASSISTIVE TECHNOLOGY INFORMATION AND REFERRAL SERVICES FOR PERSONS WITH DISABILITIES

As we enter the 21st century, advances in technology enable us to live longer and more productive lives. However, in order to benefit from this, persons with disabilities and their families must be able to locate essential services and/or devices. While these services are mandated by law, those who need the services are often not aware of where to find assistive technology services.

Assistive technology services can help individuals to increase, maintain and improve their daily lives. Yet, this can only happen when individuals have readily available information on the services they need. This can occur only when ways are found to make useful information readily available to individuals.

You are one of a small number of people in your state being asked to give your opinion on the best ways to make assistive technology information available and useful to individuals with disabilities. In order that the results truly represent the opinions of residents of your state, it is important that you complete and return the questionnaire.

Your response will be completely confidential. For mailing purposes the questionnaire has a barcode identification number. This is so that we may tally the number of returned questionnaires. Your name will never be placed on the survey. The questionnaire will take approximately 15 minutes to complete.



The Division of Information Technology at the University of South Carolina is conducting this consumer study in collaboration with RESNA Inc. as part of a contract with the National Institute on Disability and Rehabilitation Research, U.S. Department of Education.



This questionnaire is also available in braille and on diskette. If you prefer to complete this questionnaire through one of these media you may call us at collect at 803-777-8109 (9:00 AM through 4:00 PM Eastern Time).

For this questionnaire, the terms used are defined as follows:

Assistive Technology Device- any item, piece of equipment, or product system used to increase, maintain, or improve the functional capabilities of individuals with disabilities. Examples of Assistive Technology devices can include: hearing aids; wheelchairs; ramps; electronic devices that make it possible to talk with your voice; computers without a touching keyboard; and cars and vans equipped to allowed individuals with disabilities to drive.

Assistive Technology Service- any service that directly assists an individual with a disability in the selection, maintenance, or use of an assistive technology device. Examples of Assistive Technology services provided to help persons can include: help in finding available devices; help in findings ways to fund devices; help in connecting with other persons who share the same concerns; and help with reaching organizations who provide needed services.

Individuals with Disability- individuals who are, or could be helped by assistive technology services or assistive technology devices.

Information and Referral Services- provide information which helps individuals fine vice, activity, or advice on needed devices.

The results of this study will be made available to officials, representatives in our federal government, and all interested individuals. Recommendations will be made from this study which will guide the assistive technology information and referral needs policies for individuals with disabilities.

Please contact Ana Lopez-De Fede or John Alam at (803) 777-8109 with any questions or concerns about this questionnaire. Thank you for your assistance.

For Office Use Only
State:
Date//
CCE



INFORMATION ABOUT YOURSELF

	Please check I the response which best describe	s you. Check only one response.
i.	Are you a:	
	☐ Person with a disability	☐ Parent of person with a disability
	☐ Family member of a person with a disability	☐ Friend of a person with a disability
	☐ Advocate for a person with a disability	☐ Other: (Specify) ————
	If you are completing this questionnaire for a following questions as they apply to the person	• •
2.	What is your age (person with a disability)?	
3.	What disabilities do you (person with a disability	have? (Check 🗸 all that apply.)
	☐ Autism	☐ Chronic health condition
	☐ Hearing Impairments/Deaf	☐ Learning Disability
	☐ Mental Retardation	☐ Mental Health
	□ Neurological	☐ Physical Disability
	☐ Speech/Communication Impairments	☐ Visual Impairments
	Other (Specify):	
4.	Of the item(s) you checked in question #3, pleas	e give the following:
	Your Primary disabling condition	
	Your Secondary disabling condition	

AVAILABILITY OF INFORMATION

5.	During the past year, have you had to or devices?	to find informatio	n on assistive technology related services
	□ Yes	. 🗆	No
5a.	If yes, how often have you needed devices? (Check ✓ One) ☐ Weekly ☐ Other (Specify)	☐ Monthly	□ Every six months
6.	What type of assistive technology did you need help finding? (Check all that apply)	related information	on
	☐ Customization of devices ☐ Funding for devices ☐ Modification of devices ☐ Information on devices ☐ Employment services ☐ Funding for services ☐ Information on other services ☐ Information on locating services		Architectural modifications Information on Providers Information on disabilities Support/advocacy Other (Specify)



7. When you've needed information about assistive technology services or devices, where have you turned to get the information? Please rate how helpful each was in providing needed information

	Very		Not	Not
Resource	Helpful	Helpful	Helpful	Applicable
ABLEDATA	1	2	3	NA
Advocacy Organization	1	2	3	NA
Church	1	2	3	NA
Electronic Network	1	2	3	NA
Family/ Friends	1	2	3	NA
Independent Living Center	1	2	3	NA
Information/ Referral Phone Service	1	2	3	NA
National 1-800 phone number	1	2	3	NA
Person(s) with a Disability	1	2	3	NA
Phone Book	1	2	3	NA
Physician/Hospital	1	2	3	NA
Printed Materials	1	2	3	NA
Rehabilitation Counselor	1	2	3	NA
RESNA	1	2	3	NA
School	1	2	3	NA
Service Providers	1	2	3	NA
Social Worker/ Case Manager	1	2	3	NA
State or Government Agency	1	2	3	NA
Specify				
State 1-800 phone number	1	2	· 3	NA
Support Group	1	2	3	NA
Technology Fairs	1	2	3	NA
Other (Specify)	1	2	3	NA



8.	Is there an assistive technology information and referral service in your area?						
		☐ Yes	□ No				
	If yes, what area d	loes it serve?					
•							
9.		nology information vices and devices, v				lable that pi	rovided
	·	-		_			
		☐ Yes	□ No	L	Do not know		
10.	What type of info	ormation and referra	l service would	best me	et vour needs?	One that p	rovides:
10.	what type of fine	ination and referra		leet my			
			-	needs	needs	needs	know
	Information on r	ny local community					П
	Information abou	it my state					
	Information on r	my state/region of th	e country				
	Information on a	all the states and terr	ritories				
11.	Does the location	of the information	and referral se	rvice ma	ke a difference	to you?	
		□ Yes	□ No	E	Do not Know		
12.	If you had a choi	ce on the location of	the Assistive T	echnolos	gy Information 2	and Referra	l service.
 .	which would you		1001011 0 1		J		· · · · · ·
	Local	State	Regiona	l	National	Does not	matter
	п	п	П		П	г	1



13.	Would you be wreferral network?		fee to use an as	ssistive technolo	gy information	and program
		□ Yes	□ No	□ Do not kno	w	
	If yes, how much	n would you be v	villing to pay fo	r each informati	on inquiry? (C	heck 🗸 one)
	□ \$1-\$2	□ \$3-\$5	□ \$5-\$10	☐ Other (speci	fy) ————	
14.	In the past year,	did you pay for	any information	services?		
	□ Yes □	l No If yo	es, how much di	id you pay?		
14a.	Can you tell us w	hat type c°inform	nation you were s	eeking? ———		
15.		the best way to le		v to obtain infor	mation on assist	ive technolog
			Loc Lev		J	National Level
	Mail					
	Place an ad on	TV or radio	[
	Flyers					
	Phone director	y/Yellow pages	t			
	Service provide	ers				
	All of the above	ve	С			
	Other (specify))				

16.	Which of the following pieces of information would you like available to you through an information and referral service in addition to Name, Address, Phone Number and Contact Person			
	(Please che	ck 🗸 all that apply)		
	☐ Description of services/devices	☐ Eligibility requirements		
	☐ Ages Served	☐ Types of disabilities served		
	☐ Geographical area served	☐ Cost of service/device		
	☐ Hours of Operation	☐ Quality of service offered by provider		
	☐ How to apply for services/devices	☐ How to pay for services/devices		
	☐ Support/advocacy services	☐ Appeals on denial of service		
	☐ Legislative efforts	☐ Providing initial linkages with services		
	☐ Other (Specify)			
	technology services and devices? (Check	 ✓ all that apply) □ 6 Toll free telephone number 		
	☐ 2 Braille printed matter	☐ 7 Touch-Tone Telephone Hotline With		
	☐ 3 Computer access service	Punch In Codes		
	☐ 4 Computer diskette	☐ 8 Provided in language of choice (Specify)		
	☐ 5 Printed Information: Fact Sheet For	mat		
18.	•	oove (question 17) would you most prefer to use? om the above list		
19.	Do you have any additional comments?			



OPTIONAL INFORMATION

This information is optional. Please answer as many of the questions that you feel comfortable with completing in this section.

Pleas	e describe you	ur ethnic bac	kground: (Che	ck 🗸	the correct res	sponse)
	☐ Black	☐ White	☐ Hispanic	□ Na	ative American	
	☐ Asian	☐ Other (Spe	cify) ————			
What	is the highest	level of educ	cation you con	nplete	d?	
	☐ Elementa	ry School	☐ High Sch	nool	☐ College	
	☐ Graduate	School	☐ Other —			
What	is your annua	al family inco	me? (Please ⊌	/ the	range of your	annual income)
	☐ Less than	1 \$10,000	5 10,000 - \$19,999			□ \$ 20,000 - 29,999
	□ \$ 30,000	- 39,999	40,000 - 49,999			□ above \$50,000
Do yo	ou live in a:	□ Ri	ural area or fa	rm	☐ Small tow	vn (less than 3,000)
		□ Ţ;	own (3,000 to	20,000	0)□ City (ove	r 20,000)

We will be preparing a one page summary of the findings of this survey. If you wish to receive a copy, please print your name and address on the attached postcard and mail it to us or you may call 1/803-777-8109 to request a copy of the findings.

Thank you for taking the time to complete this questionnaire.



The Division of Information Technology, University Affiliated Program, The University of South Carolina would like to thank you for taking the time to fill this questionnaire for this very important survey study.

Fold here and staple or tape. Please drop in the mail.



23020 F121 Feasibility Study

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Practices In The Assistive Technology Information and Referral Field A Research Project of the Division Of Information Technology of the Center for Developmental Disabilities

University of South Carolina Columbia, SC 29208

The National Legiture on Detability and Rehabilitation Research, U.S. Department of Education has funded the Center for Levelopmental Disabilities (CDD) to conduct a study to determine the feasibility of establishing an assist the technology national information and program referral (I&R) network. We are surveying 18th providers to determine the current practices in Assistive Technology I&R systems. Additionally we want to develop and assess criteria which would guide the development of a national Assistive Technology I&R Network. As practitioners with an interest in the Assistive Technology I&R field your input is essential. The results of this study will help to make policy recommendations regarding the a sistive technology needs of persons with disabilities.

Please take the time to complete this survey yourself or have someone in your office complete the form. For questions or information, please contact Ana Lopez-De Fede at (803) 777-8109.

For your time and effort in completing this survey a copy of the "National Directory of Information and Program Referral Assistive Technology Services and Networks" will be sent to you in December, 1992.

A barcode has been placed on this survey to classify survey responses by type of assistive technology service. The barcode is used only for statistical coding purposes and will not link a completed survey to a specific individual and/or agency. We ask that you not remove the barcode or duplicate this survey. Additional surveys can be obtained by calling John Alam at (803) 777-8109.

Thank you for your participation in this important project.

Please mail by March 15th, 1991 using the enclosed envelope.



For our records, please provide the following information:

Name and Title of Person completing the form:	-
Agency/Organization	_
Address:	_ _
Phone: (), ext TDD: (); (800)	
Name of Assistive Technology (AT) I&R Service(s):	_
Director of AT I&R Services:	_
DEFINITIONS:	1 1 1 1 1 1
For this survey, terms used are defined as follows:	1
Assistive Technology (AT) Device - any item, piece of equipment, or product system, used to increase, maintain, or improve the functional capabilities of individuals with disabilities.	
Assistive Technology (AT) Service - any service that directly assists an individual with a disability in the selection, acquisition, maintenance, or use of an assistive technology device.	
Caller - any person contacting the AT I&R service for information, either by telephone, mail, walk-in or electronic access.	1
Consumer - a person with a disability.	i
Individual with Disabilities - any individual who is or could be helped by assistive technology devices or assistive technology services.	
Information and Referral (I&R) - the process through which assistive technology information is provided to individuals by identifying organizations or individuals that can provide the appropriate services.	ļ ;
Information and Referral (I&R) Specialist - Person responding to caller.	
Provider - any agency, organization, program, or individual included for referral purposes in your AT I&R service information.	1

ERIC Full Text Provided by ERIC

TYPES OF SERVICES AVAILABLE

1a.	How would you classify your AT I&R services? (Please check ✓ only one)							
	☐ The central focus and responsibility of the agency							
	☐ A formally designated service	e of the agenc	у					
	☐ Not a formally designated se	rvice, but prov	rided as requested or as ne	eded by consumers				
				m vor				
1b.	If your agency is not involved		arrangement for deliver:	ng A1 1∞K services, is a □ No				
	formal arrangement being cons	adered?	L res	- 140				
1c.	In your opinion, how essential	is AT I&R re	elative to other services p	provided by your agency:				
	(Please check only one)							
	□ Very Essential □ E	Essential	☐ Somewhat Essential	☐ Not Essential				
		-424	door your ag	anay rassiya in an ayaraga				
2a.	Approximately how many assimonth for each of the following			ency receive in an average				
	Information and referral		Direct advocacy or	behalf of				
			caller with other ag	gencies				
	Direct referral and scheduling		Networking with o					
	with agencies or organizations		(e.g. medicaid/medicare)					
	Follow-up services with callers		Information on regional					
	and providers		programs/services					
	Information on national		Other (specify)					
	programs/services		ı					
2b.	Which of the following I&R	AT services a	nd/or AT equipment ser	vices are provided by your				
	agency: (Please check 🗸 all th	at apply)						
	☐ Equipment	☐ Access	sibility	☐ Funding				
	☐ Lease/Rental/Loan	☐ Assess	sment/Evaluation	☐ Fitting				
	☐ Ordering	☐ Fabric	ation	☐ Training				
	☐ Maintenance/Repair	☐ Other	(Specify)					

ERIC

POPULATION SERVED

Approximately, how many assistive technology information and referral requests does your

	agency receive in a month on average from the following:
	Monthly # of requests
	General Public
	Persons with specific disability (specify)
	Persons with disabilities or their families
	A target group (specify)
	Group with specific AT (specify)
	Advocacy Organizations (specify)
	Direct Service Providers
	Planning/administrative staff of state service agencies
	Legislators
	Medical Personnel
	Others (specify)
3b.	On which of the following are your AT I&R services concentrated: (Check / all that apply)
	☐ Adaptive Equipment ☐ Computer (Hardware/Software) ☐ AT Services
	☐ Employment ☐ Support Services ☐ Other (specify) —————
4a.	Does your AT I&R serve all age groups?
	If no, what primary age group/s are served.
4b.	Does your AT I&R serve all disabilities?
	If no, what disabilities are served?
	1110, What districts are served.
5.	What is the geographic area covered by your AT I&R service? (Please check all that apply)
	☐ United States (all 50 states and territories) ☐ United States (contiguous 48 states only)
	□ State(s) (specify)
	County(s)
	□ City/Town(s) ————————————————————————————————————
	Other (specify)

ERIC

3a.

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ACCESS TO AT I&R SERVICES

6a.	In an average month, how many individuals conta	act your agenc	y using t	he following	methods(s):			
	Telephone (800 #) Mail							
	Telephone (Toll call) Compu	ter access (spe	cify)					
	TDD/TTY Other	specify)						
6b.	Hours/Days of AT I&R service operation:							
6c.	Describe after hours arrangements: (Please circle	e only one)						
	a. Answering machine b. No arrangements	c. Other (desc	ribe) —					
	ORGANIZATIONAL STRUCTURE							
7.	How many of the agency's AT I&R staff are: (P	lease write in t	he # of p	ositions for ea	ach category)			
	Category	Full	Part	Volunteer	Graduate			
		Time	Time		Assistant			
	Administrative staff							
	Information and Referral Specialists							
	Support Staff (Secretary/Data entry staff)							
8.	How many of the AT I&R specialists in your a			ing qualificat	tions:			
		Number	of Staff					
	Professional Degree Doctoral level	l	1					
	Professional Degree Master level	l	1					
	Professional Degree Bachelor level] 1- A :]					
	Paraprofessional (Associate Degree or equiva	lent) []					
	Other (specify)	l	J					

ERIC PROVIDED BY ERIC

TRAINING ACTIVITIES

9a.	Do you provide training for entry level AT	I&R staff?	□ Yes	□ No
	If yes, specify the type and length of training pro	vided: ——		
-				
9b.	What kind of written training materials do	you use? (Plca	se check all	✓ that apply)
	☐ Descriptive	☐ Paper/peno	il skill deve	elopment exercises
	☐ Knowledge/competency based materials	Other (spec	ify) ———	
9c.	How often is in-service training provided	to I&R Specialis	sts? (Plea	ase check 🗸 only one)
	☐ Monthly ☐ Semi-Annually ☐	☐ Annually	Other (specify) —————
9d.	Indicate the method(s) you use to provide (Please check / all that apply.)	training for ent	ry level an	d in-service staff.
	Method	Entry Level Sta	ff	In-service
	Lectures			
	Materials to test competency skills and knowled	ge 🗆		
	Case Simulations			
	Supervision			
	Case review			
	Professional Conference			
	Other (Specify)			

(Please attach samples of these materials with this survey)

ERIC

4. 116

ORGANIZATIONAL BUDGET

10a.	What is the total annual l	oudget of your A	T I&R agency?	·				
10b.	Approximately, what pe each of the following?	rcentage of the	total agency budget is allocated	to AT I&R	spending for			
	Staff _	%	Training of Staff	%				
	Technical Equipment _	%	Data Collection	%	•			
	Updating I&R system _	%	Publicity _	%				
	Evaluation Efforts _	%	Telephone costs	%				
	Othe	r (specify)		_%				
				5 1				
		INFORMA	TION MANAGEMENT					
11a.	Do you currently use management?	or are you pl	anning to use a computerized	i system for	information			
	☐ Currently use	e 🗖 Planr	ning to use	to use				
	Carronay ass	, _ 	· ·					
			g to use, please list the followi					
	a. Hardware used							
	b. Software used -							
	c. Data Management use	ed for generating	reports ————	· · · · · · · · · · · · · · · · · · ·				
	U. ITIOUCIII	d. Modem ————————————————————————————————————						
	e. Other ———							
			1 1 4 m Y 0 m 4 m 1 m 1 m 1 m 1 m 1 m 1 m 1 m 1 m 1	□ Yes	□ No			
11b.			andard AT I&R taxonomy?					
	If yes, please identify: —			·				
11c.	What is the approxima	ite number of se	ervices/equipment listings in yo	ur AT I&R s	ystem (include			
110,			s, information sources, etc.)		· · ·			
	an brogramo, marrido		·, - · · · · · · · · · · · · · · · · · ·		_			



11d.	How is your infor	mation organ	nized? (Please cho	eck 🗸 all that apply)
	☐ Date of entry in	ı your service		□Location of pro	vider
	☐ Availability of	services		☐ Cost of service	
	☐ Specific Disabil	lity matched t	o AT service	☐ Eligibility requ	irements
	☐ Age requiremen	nts for service		☐ Training for ut	ilization of AT device
	☐ Financing of A	T devices/serv	vices	☐ Engineering se	rvices for AT devices
	☐ Evaluative serv	ices		☐ Loan and/or le	ase programs
	☐ Groupings (Spe	cify)		☐ Other (Specify)
11e.				(Please check / all	
	□ Mail	- -			□ Diskette/CD-ROM
	☐ Electronically	□ Pamphle	ts/Brochures	☐ Other (describe	s)
11f.	How do you verif	y the accurac	y of information	in the AT I&R syst	em? (Check / all that apply)
	☐ Periodic rando	om check of a	ll information by	AT I&R staff	
	☐ Feedback or c	omplaints abo	out accuracy of in	formation from cons	umers and/or their families
	☐ Feedback or c	complaints abo	out accuracy of in	formation from profe	essionals using the system
	☐ Systematic ve	rification of A	T I&R database	Other (spe	ecify) —
11g.	Please describe t	he most effec	tive method of c	ollecting informatio	on for your AT I&R system?
12a.	How is your AT	I&R databas	se information m	aintained? (Please	check 🗸 all that apply)
	☐ Hardcopy Dir	ectory	□ Rolodex	☐ Microcomput	er Database
	☐ Mainframe D	atabase	☐ Other (specify	y) —	

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12b.	Which of the following are used to update listings: (Please check / all that apply)								
		Rely on providers to notify of changes							
		Use information from directories							
		Use batch processing to make database changes.							
		☐ Monthly ☐ Semi-Annual ☐ Annual ☐ Other —							
		Mail printouts to providers for their review							
		☐ Monthly ☐ Semi-Annual ☐ Annual ☐ Other ——————							
		Contact providers by phone to update information							
		☐ Monthly ☐ Semi-Annual ☐ Annual ☐ Other —————							
		Make on-site visits to obtain information							
		☐ Monthly ☐ Semi-Annual ☐ Annual ☐ Other —————							
		Other (Specify)							
13.		other databases do you use to supplement the information in your own database? se check all that apply) RIC NARIC ABLEDATA Other (specify)							
14a.	Are t	here other AT I&R provider(s) in your area? \square Yes \square No \square Do not know							
14b.	List 1	the types of services provided by the other I&R providers in your area?							
		[If available, please attach a mailing list of these providers]							
15a.		ou share databases with other I&R providers?							
	If ye	s, how do you share those databases? (Please check / all that apply)							
		Floppy disks							
	□ F	Printed copy							
	If no.	, why not (specify)							

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	☐ Yes	□ No						
15c.	If yes, please check the type of services y	ou refer c	allers to ou	ıtside y	our ope	rating a	rea:	
	☐ Regional I&R services		□ Natio	nal I&F	service	s		
	☐ Research and Engineering Technology	centers						
	☐ Federal government organizations (specify	·)						_
	☐ Advocacy organizations (specify) ———						<u> </u>	
	Others (specify)							_
16.	How high a priority would you place on m Please circle the appropriate response. 1=Very low priority; 2=Medium priority						R servic	es?
	Increase level of AT I&R funding			1	2	3	4	NA
	Expand services			1	2	3	4	NA
	Expand computer capacity			1	2	3	4	NA
	Hire more paid staff			1	2	3	4	NA
	Obtain more training for AT I&R staff			1	2	3	4	NA
	Improve quality of information			1	2	3	4	NA
	Networking with other AT I&R systems			1	2	3	4	NA
	Increase technical support			1	2	3	4	NA
	Other (specify)			1	2	3	4	NA
17.	How significantly do the following interf with making desired changes in AT I&I 1=Not Significant; 2=Somewhat significant;	R services	? Please ci	rcle the	appropr	iate resp	onse.	l/or
	Lack of standardized systems across AT I&R	services		1	2	3	4	NA
	Lack of compatible hardware			1	2	3	4	NA
	Lack of training or expertise of staff			1	2	3	4	NA
	Difficulty in obtaining resources on existing se	ervices		1	2	3	4	NA
	Difficulty in providing area specific resources			1	2	3	4	NA
	Lack of funds			1	2	3	4	NA
	Lack of staff			1	2	3	4	NA
	Other (specify)			1	2	3	4	NA
		8	· 1 20					

Do you refer callers to AT I&R services outside of your operating area?

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15b.

18a.	How does your AT I&R ser	vice follow-ı	up on informat	tion request	s to de	termine	whethe	r the	
	information provided was useful? (Please check / the method used by your agency)								
☐ Follow-up on all information requests ☐ Follow-up on a sample of information requ								uests	
	☐ No formal policy regarding	ng follow-up	on information	requests					
18b.	How are these follow-up ser	rvices condu	cted?						
	☐ Mail ☐ Telephone	In Pers	Son	specify) —		_			
18c.	How long after initial conta	ect is follow-	up performed?	•					
	□ 1 - 2 months □ 2	- 6 months	□ 1 year	Other (Specify) ——			
	<u> </u>			<u> </u>					
		OUTR	EACH EFFO	RTS					
19a.	How effective are each of t	he following	in publicizing	and reachi	ng targ	et audie	nces of	your	
	AT I&R service. Please cir	rcle the appro	opriate response	•					
	1=Not Effective; 2=S	omewhat Effec	tive; 3=Effective;	l=Very Effecti	ve; NU =	Not Used	•		
F	Personal contact			1	2	3	4	NU	
7	Telephone Directory			1	2	3	4	NU	
(Conference Displays			1	2	3	4	NU	
1	Newsletters, brochures, etc.			1	2	3	4	NU	
5	Speaking Engagements/Interviev	ws		1	2	3	4	NU	
1	Direct mailings			1	2	3	4	NU	
]	Public relations (Ads, PSAs, Mo	edia stories e	tc.)	1	2	3	4	NU	
(Other (specify)	-		1	2	3	4	NU	
19b.	How does your AT I&R s	ervice measi	are the effectiv	eness of ser	vices pi	ovided	to calle	rs?	
	(Please check / all that ap	ply)							
	☐ Consumer satisfaction surve	ey Desc	criptive statistic	s on service:	and/cr	callers			
	☐ External evaluation	☐ Form	nal agency serv	ice evaluatio	n (desc	ribe) —	-		
	Other (specify)								

(Please attach samples with this survey)



1 3. 2 121

NATIONAL ASSISTIVE TECHNOLOGY INFORMATION AND PROGRAM REFERRAL NETWORK

This study is considering the feasibility and desirability of establishing a National Assistive Technology Information and Program Referral Network. A number of suggestions have been made as to the organization of such a network, what functions it should perform, and how it should be funded. We would like you to reflect upon your experience and offer your judgement on several points regarding a national AT I&R network.

20.	Could a national AT I services?	I&R Network	benefit your callers a	nd expan	d your	ability 1	to provi	de
	- 7	Yes 🗆 No	☐ Do not know					
I	f yes, please describe how a	a national syste	em could be of benefit.					<u> </u>
21.	How significantly would of a national AT I&R		•			_		i on
	1=Not significant; 2	=Slightly signific	ant; 3=Significant; 4=Highly	significant;	NA=Not	applicable	:	
1	Local agency taxonomies			1	2	3	4	NA
1	Local agency resource files			1	2	3	4	NA
1	Hardware compatibility			1	2	3	4	NA
;	Standardized criteria for AT	Γ						
	service delivery			1	2	3	4	NA
	Competing for fiscal resour	rces		1	2	3	4	NA
	State laws which guide the	delivery						
	of services	·		1	2	3	4	NA
	Federal laws which hinder	collaboration		1	2	3	4	NA
	Conflicting policy among for	ederal						
	agencies serving the disab	bled		1	2	3	4	NA
	Limited fiscal resources to	provide						
	both state and national sy	ystems		1	2	3	4	NA
	Other(s) (specify)		<u> </u>	1	2	3	4	NA
				1	2	3	4	NA



10

22. If a national AT I&R network were feasible, which of the following organizational arrangements would best meet your agency and clients' needs? Please circle the appropriate response for each.

1= Not desirable; = Somewhat desirable; 3= Desirable; 4= Highly desirable; NA= Not applicable

One national AT I&R provider with a multilevel system of support services for local, state and national systems	1	2	3	4	NA
One AT I&R provider at the national level	1	2	3	4	NA
One administrative clearinghouse program with I&R provided by member services/systems	1	2	3	4	NA
One administrative clearinghouse program with information and referral provided by 4-6 regional centers		·			
One AT I&R provider for each state	1	2	3	4	NA
Multilevel system with combination of local, state and national AT I&R services	1	2	3	4	NA
Other (Specify)	1	2	3	4	NA
	1	2	3	4	NA

23. Based on your experience, rate the following funding processes on the likelihood that local and state I&R agencies would fund a national AT I&R network. Circle the appropriate number for each.

1=Would not fund; 2=Would probably fund; 3=Would likely fund; 4=Absolutely would fund; NA=Not applicable

Local and state agencies match funding for a national AT I&R network	1	2	3	4	NA
Local and state agencies subscribe to a national AT I&R network	1	2	3	4	NA
Local and state agencies engage in a fee for services arrangement with a national AT I&R network	1	2	3	4	NA
Local and state agencies support a federal initiative to fund a national AT I&R network	1	2	3	4	NA
Other (specify)	1	2	3	4	NA
	1	2	3	4	NA



24. Based on your experience, evaluate the helpfulness of the following functions and services provided by a national AT I&R network: Please circle the appropriate number for each response

1= Not helpful; 2= Slightly helpful; 3= Helpful; 4= Very helpful; NA= Not applicable

Provide assistance in locating AT I&R services					
at the local, state, and national level	1	2	3	4	NA
Provide assistance with hardware/software selection	1	2	3	4	ΝA
Centralized system to handle AT I&R inquiries					
on a regional level	1	2	3	4	NA
Training to establish AT I&R systems	1	2	3	4	NA
Training in operating an on-line AT I&R system	1	2	3	4	NA
Training and technical support for AT I&R specialist	1	2	3	4	NA
Play a lead role in coordinating a unified					
approach to AT I&R service delivery	1	2	3	4	NA
Technical support for designing AT I&R database structure	1	2	3	4	NA
Develop AT I&R standards for data compatibility					
and data interchange at all national levels	1	2	3	4	NA
Provide a distributable AT I&R database	1	2	3	4	NA
Provide regional databases on CD-ROM	1	2	3	4	NA
Assist in developing evaluation network for					
local, and regional AT I&R systems	1	2	3	4	NA
Assist in developing an AT I&R services taxonomy	1	2	3	4	NA
Formulate strategies for AT I&R outreach efforts					
to increase public awareness of AT services	1	2	3	4	NA
Promote the visibility and impact of AT I&R					
services on serving the needs of the disabled	1	2	3	4	NA
Database on AT conferences on local, state			_		
and national levels	1	2	3	4	NA
Other (specify)	1	2	3	4	NA

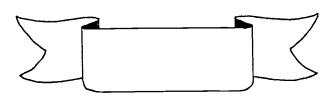


25. Given the concept of a national AT I&R network is relatively new, how confident do you feel about responding to questions about a national network.

Please circle the response which best states your confidence level.

1 = Not confident 2 = Somewhat confident 3 = Confident 4 = Very confident

Do you have any additional comments?							
						_	
							
							



The Center for Developmental Disabilities, University Affiliated Program of South Carolina, University of South Carolina, would like to thank you for taking the time to complete this survey. As we mentioned earlier, the results of this survey will be instrumental in the formulation of federal policy on information and program referral in the area of assistive technology. Again, thank you for your time.

APPENDIX C

GLOSSARIES

&

DEFINITION OF TERMS

Consumer Sub-Group Codes

resna RESNA, Inc.

nis National Information System

scsis South Carolina Services Information System

nd North Dakota nc North Carolina

il Illinois oh Ohio

tn Tennessee

bbn Bulletin Board Network users

tdd Telecommunication Device for the Deaf subscribers

vis American Council of the Blind

se Southeast Parent Empowerment Group

bnt BabyNet

ygr Independent Living Center for Youth

tech Foundation for Technology Access Centers

Abbreviations

Ad	Advertisement	F/T	Full Time
Admin	Administrative	Fam	Family
Adv	Advocacy	Fed	Federal
Applic, Aplic	Applicable, Application	Feedbck	Feedback
Archi	Architectural	Geo	Geographical
Assist	Assistive	Gp	Group
Asst	Assistance	Gvt	Government
AT	Assistive Technology	Hrdwr, Hard	Hardware
Bk	Book	Hrs	Hours
Cap	Capacity	I&R	Information and Referral
Classf	Classification	IBM Nat'l Supt	IBM National Support
Comm	Community	Impct	Impact
Comp	Computer	Inc	Increase
Conf	Conferences	Indep	Independent
ConfDisplays	Conference Displays	Info	Information
Cons	Consumers	Init	Initial
Consult	Consultation	Inq	Inquiries
Coord	Coordinating	Intl, Int	International
Couns	Counselors	Intrview	Interviews
Dbase	Database	Lang	Language
Descp, Desc	Description	Legs	Legislative
Descrip	Descriptive	Liv	Living
Desgn	Design	Lrng	Learning
Dvcs	Devices	Maintain	Maintenance
Devp, Dev	Development, Develop	Med	Medium
Direc, Dir, Dire	Directory	Mem	Member
Dis, Disab	Disability	Mgr	Manager
Doc	Document	Mo	Monthly
Elect	Electronic	Mos	Months
Eligib, Elig	Eligibility	Modifi	Modifications
Eng	Engineering	Natl, Nat	National
Equip	Equipment	Neuro	Neurological
Estb, Est	Establish	Netwrk	Network
Eval	Evaluation	Newsltrs	Newsletters
Exp	Expand	Orgn	Organization(s)

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United States US Part Time P/T UHI Utilization PR. **Public Relations** Vis Visibility Pd Paid Wks Weeks Pers Persons, Personal Yel Yellow Pgs **Pages** Yr, Yrs Year(s) Phone, Tel Telephone

Phys Physical
Plan/Admin Planning/Administrative

Prnt Printed
Prof Professional
Prog Programs
Proj Project
Prov Provider
Qual Quality
Ref Reference
Regnl Reg Regional

Regnl, Reg Regional
Rehab Rehabilitation
Req, Reqrm Requirements
Resp Response

Resrch/Eng Research and Engineering

S.C. South Carolina
Sche Scheduling
Sec Secondary
Signif, Sig Significant

Spec Specialists, Special

Specif Specific
Stdz, Standard Standardize
Std(s) Standard(s)
Strategie Strategies

Supt, SupptSupportSvcs, Svc, ServServicesSystsSystemsTechgy, TechTechnolog

Techgy, Tech Technology
Tech Technical
Terr Territories
Trng, Train
Training

Univ. Of S.C. University of South

Carolina

Acronyms

4T's Technology, Training, Taxonomy, and Turf
ADD Administration on Developmental Disabilities

AT Assistive Technology

CDD Center for Developmental Disabilities
CD-ROM Compact Disc-Read Only Memory

CRTS Center for Rehabilitation Technology Services

DOS Disk Operating System

ERIC Educational Resources Information Center

FIND Forum for Information Networking on Disabilities

HS High School

I&R Information and Referral

IMS Information Management System

MH Mental Health

MR Mental Retardation

NARIC National Rehabilitation Information Center

NIDRR National Institute on Disability and Rehabilitation Research

NIS National Information System, USC

NREN National Research and Education Network

NSCPD National Support Center for Persons with Disabilities, IBM

P.L. Public Law

RAM Random Access Memory

SCAN Shared Communication Assistance Network
SCSIS South Carolina Services Information System

SDD Service Delivery Directory

TA Technical Assistance

TCP/IP Transmission Control Protocol/Internet Protocol
TDD/TTY Telecommunications Device for the Deaf/Teletype

TLC The Logical Choice

UAP University Affiliated Program
USC University of South Carolina

UWASIS United Way of America Service Identification System

VANS Value Added Network Services

Disabling Conditions

The following are examples of conditions in each category; definitions of conditions are not limited to examples cited here.

Disabling Conditions	Examples
Hearing Impairments/Deaf	Congenital hearing impairment; Deafness; Hard of hearing; Loss of hearing
Neurological	Alzheimer's Disease; Cerebral Palsy; Muscular Atrophy; Multiple Sclerosis
Speech/Communication Impairments	Aphasia; Communication disorder; No vocal chords or voice box
Chronic Health Condition	Asthma; Coronary heart disease; Kidney disease; Diabetes; High blood pressure
Learning Disability	Lack of attention span; Cannot read or write
Mental Health	Depression; Schizophrenia; Senility
Physical	Arthritis; Spina Bifida; Osteoporosis; Dislocated or broken hip; Hands/feet deformed; Polio; Paraplegia
Visual Impairments	Cataracts; Glaucoma; Retina degeneration; Blindness
Other	Cancer; Rare Syndrome; Developmental delay



Definition of Terms

Access to AT I&R Service: The intentional use of methods that make available technology-related information and referral services to consumers.

Assessment: A complete analysis of an individual's situation with regard to the need for, and potential benefits of, the appropriate types of assistive technology or technology-related services that could enhance his/her life.

Assistive Technology Device: Any item, piece of equipment, or product system used to increase, maintain, or improve the functional capabilities of persons with disabilities. Examples of Assistive Technology Devices can include: hearing aids, wheelchairs, ramps, alternate computer keyboards, and automobile modification devices.

Assistive Technology Service/Provider: Any service that directly assists an individual with a disability in the selection, maintenance, or use of an AT device. Examples of Assistive Technology Services can include: help in finding available devices, help in finding ways to fund devices, and help with reaching organizations who can provide needed services.

Consumer: Individual, or someone responding for an individual, who is, or could be, a user of AT information and program referral services.

Disability: "In the health context, disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being." (WHO, 1980)

As used by rehabilitation professionals, refers to a medical condition that causes a handicap. Physicians, on the other hand, "call the result of the medical impairment a 'disability', referring to a narrower range of phenomena than that referred to by handicapped." (Wright, 1980:69)

The Harris pollsters defined survey respondents as being disabled if: (1) the individual had a disability or health problem that prevented them from participating in work, school, or other activities; (2) the individual said that he or she had a physical disability; or (3) the individual considered himself or herself disabled, or said that other people would consider them disabled. (NCH, 1988:12)

Equipment: A general term to include the entire field of products, aids, devices, or other apparatus/hardware that is commercially available, or that can be custom fabricated to assist individuals with disabilities in functioning independently.

Evaluation: A hands-on, in-person, process whereby an individual with a disability is tested, measured, observed, and questioned for the purpose of determining the most appropriate and beneficial technology for his/her individual situation. Generally, evaluations are performed by specialists such as occupational or physical therapists, vendors, rehabilitation engineers, orthotists, prosthetists, or others with the adequate knowledge, skills, and abilities to provide these services.

Fabrication: The actual hands-on design, construction, assembly, or other process involved in creating a customized product or device that will solve a specific problem faced by an individual with an impairment.



Fitting: The process of installing, adjusting, and testing a product, device, piece of equipment, or other custom fabrication as it applies to benefitting an individual in some way.

Follow-Up: An on-going quality assurance service performed to determine if a particular information or referral made is appropriate and effective. Generally, a follow-up service will be performed by the Information and Referral Specialist who performed the original assessment and recommendation.

Formal Information Dissemination Sources: Formal entities (e.g., agencies, organizations, groups, and individuals) that are recognized because of their funding base, affiliation, or incorporation status.

Implementation: Refers to all of the events, actions, and decisions involved in putting an idea into use.

Individuals with Disability: Individuals who are, or could be, helped by AT services or AT devices.

Informal Information Dissemination Sources: Information sources that individuals turn to for information but which have no formal ties to any established information agency or organization (e.g., tribal leaders for Native American tribes).

Information: Knowledge provided to a consumer, family member, provider, or other advocate to facilitate the delivery of appropriate technology that will help to enhance an individual's functional capabilities.

Information and Program Referral System: A system comprised of individual I&R services linked together under one mission or purpose. The proposed National Assistive Technology Information and Program Referral Network is classified as an I&R System.

Information and Referral Broker: A paid or volunteer staff person adequately trained and proficient in the direct provision of information, referral, and follow-up in service inquires.

Information and Referral Processes: The process through which information is provided to individuals by identifying organizations or individuals that can provide the appropriate services(s).

Information and Referral Services: Services providing information which helps individuals find a service, activity, or advice on needed devices.

Information and Referral Source(s): A source that helps individuals find the services that best alleviate or eliminate their need for information. An I&R service can be a public, private, profit, or non-profit organization. An I&R service is not a hotline or crisis line, which emphasizes a counseling function.

Information and Referral Specialist: A paid staff person adequately trained and proficient in the direct provision of information, referral, and follow-up in service inquires.

Information Database: A collection of data stored in an organized structure which can easily be used for retrieval and sharing.

Information Dissemination: The wide distribution of information or knowledge by a variety of ways to potential users or beneficiaries.



Information Use or Utilization: The application of relevant and purposeful data to a new use or by a new user. It differs from knowledge use in that it may back a scientific research foundation or consensual validation of its quality.

Maintenance/Repair: A service that must be performed routinely or as needed to keep products, devices, or other equipment functioning at the maximum level. Maintenance and repair can be performed by anyone who is skilled to do so, but is routinely performed by durable medical equipment vendors and other specially-trained service technicians.

Ordering: Activities to acquire specific products, devices, materials, or other equipment to be used in the application of assistive technology services. Ordering usually involves securing adequate payment for needed assistive technology.

Provider: Any agency, organization, program, or individual included for referral purposes listed in a retrievable information database.

Recommendations: A specific professional opinion with regard to the types of aids, devices, equipment, or other services within the field of assistive technology that might improve an individual's level of functioning or quality of life.

Referral: Directing or otherwise linking someone to the proper professional, program, service, or agency that will provide or play an essential part in facilitating the delivery of technology- related information.

Technology Transfer: The process through which the results from basic and applied research are put into use. Technology transfer has both a hardware and software component. The software component provides an information base for communicating.

Training: A process whereby an individual with a disability, family members, or other appropriate personnel are taught how to use a specific piece of assistive technology, product, or service.

These definitions have been adopted from the following:

- Technology Related Assistance for Persons with Disabilities Act of 1988
- Alliance for Information and Referral Services
- Center for Rehabilitation Technology Services, South Carolina Vocational Rehabilitation Department



Assistive Technology Services*

- Assessment: A complete analysis of an individual's situation with regard to the need for, and potential benefits of, the appropriate types of assistive technology or technology-related services that could enhance his/her life.
- Equipment: A general term to include the entire field of products, aids, devices, or other apparatus/hardware that are commercially available, or that can be custom fabricated to assist individuals with disabilities in functioning independently.
- Evaluation: A hands-on, in-person, process whereby a disabled individual is tested, measured, observed, and questioned for the purpose of determining the most appropriate and beneficial technology for his/her individual situation. Generally, evaluations are performed by specialists such as occupational or physical therapists, vendors, rehabilitation engineers, orthotists, prosthetists, or others with the adequate knowledge, skills, and abilities to provide these services.
- Fabrication: The actual hands-on design, construction, assembly, or other process involved in creating a customized product or device that will solve a specific problem faced by an individual with an impairment.
- Fitting: The process of installing, adjusting, and testing a product, device, piece of equipment, or other custom fabrication as it applies to benefitting an individual in some way.
- Follow-Up: An ongoing quality assurance service performed to determine if a particular application or technology is appropriate and effective. Generally, a follow-up service will be performed by the professional, or equally qualified professional who performed the original evaluation, prescription, and recommendation.
- Information: Knowledge provided to a consumer, family member, provider, or other advocate to facilitate the delivery of appropriate technology that will help to enhance an individual's functional capabilities.
- Maintenance/Repair: A service that must be performed routinely or as needed to keep products, devices, or other equipment functioning at the maximum level. Maintenance and repair can be performed by anyone who is skilled to do so, but is routinely performed by durable medical equipment vendors and other specially trained service technicians.



- Ordering: Activities to acquire specific products, devices, materials, or other equipment to be used in the application of assistive technology services. Ordering usually involves securing adequate payment for needed assistive technology.
- Recommendations: A specific professional opinion with regard to the types of aids, devices, equipment, or other services within the field of assistive technology that might improve an individual's level of functioning or quality of life.
- **Referral:** Directing or otherwise linking someone to the proper professional, program, service, or agency that will provide or play an essential part in facilitating the delivery of assistive technology.
- Training: A process whereby the individual with a disability, family members, or other appropriate personnel are taught how to use a specific piece of assistive technology, product, or service.

Developed by Center for Rehabilitation Technology Services (CRTS), South Carolina Vocational Rehabilitation Department

APPENDIX D

SERVICE TAXONOMY COMPARISONS

SERVICE TAXONOMY COMPARISONS

SC, NIS, NM, OK, LA, WI, MO, HI, N.E., Info Cir*

	NIS	NM	OK	1.4	WI	MO	HI	N.B.	INFO CTR
ASSISTIVE TECHNOLOGY/EQU IPMENT	SPECIALIZED EQT.	SPECIALIZED EQT. MEDICAL RQT.	SPKTALI ZE EQT.	SPECIALIZED EUT.	ASSISTIVE TECHNOLOGY	SPECIALIZED EQT.	SPECTALIZE D EQT.	A.S.ISTIVE TECH	Болгмт
Agricultural Equipment									Adaptive Farming Equipment
	Augmentative Communications Sensory Aids, Blind Sensory Aids, Deaf		Augmentive Comm Deviœs		Speech -Arificial Speech, Aug Com -Oral Speech Aids, Artif Larynx			Augmentativ e Commun	Augmentative Communication -Artificial Larynx -High Tech Expressive Communic. Aids -Other Writing Aids -Typewriters -Voice Amplifiers -Speech Aids, Access - Other
Automobile Adaptations	Vehicle Adaptation	Automobile Adaptation	Automobile Adaptation	Automobile Adaptation		Automobile Adaptation			Vehicle Evalu, Modif Auto/Van -Accessories -Alam Sys -Hand & Foot Controls -Indiv Models -Lifts & Ramps -Transport, Driving Aids -Travel Aids
		Car Scats		Infant Car Seats					

SET

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INFO CTR	Adapted Clothing -Accessories -Other		Computers -Hardware & Peripherals -S. stware	Computer Applications -Educa Related Assist. Tech -Home Related A T -Leisure Related A T -Work Related A T	Computers -Has tware & Periphe rals -Software	Urinary, Ostomy Care	Emergency Safety Aids - Identification
N.E.			Computer Hardware/Sof tware	Computer Hardware/Sof tware			
Ш	Clothing		Computer Eqt/Software				
MO			Computer Eqt/Applications	Computer Eqt/Applications			
WI	Daily Living -Adapted Clothing -Aids for Daily Living		Computer Access Aids Computer Input Access Aids -Computer Display Access				
LA LA	Adapted/Modifie d Clothing	Building Modifi cations Specs	Computer Eqt.				
OK							
NM	Adapted Clothing		Computer Hardware Computer Eqt./Application	Computer Eqt./Application Computer Software			
NIS	Special Needs Clothing		Computer/Aids & Devices				
38	peted	See Information & Technical Asst. -Rules & Regulations	Computer Hardware	Computer Software		Continence Products	Demonstration Center Emergency Identifiers
ERIC*	<u> </u>						

SC. NIS	NW	30	5	IM)MO	HI	N.E.	INFO CTR
Energency Response Eqt.				Control & Signaling - Emergency Call Systems - Environ Control				Alam/Emerg Call Systems -Adaptive Alam Device -Adaptive Signal
				-Local Alarm/Call Systems -Robotics				Levice - Evacuation Devices - Other - Paging Systems - Personal Emerg Response Sys
				See Accessibility				Adapted Fumiture -Beds -Other
Environ. Control Devices/Switches	Electronic Envir	Elect. Envir. Control Device	Elect. Envir. Control Device	See Alerting Devices	Elect. Envi Control Der ice			Envir Controls -Doors, Windows -Systems, Switches
Equipment Resale			Eqt. for Sale		Eqt. for Sale	Eqt. for Sale by owner		Used EqtDonation -Loan -Purchase
Exercise Equipment- Adapted	Toys/Sports Eqt.			Recreation -Adapted Exercise Aids -Adapted Toys -Adapted Sports, Leisure				Recreation Aids -Adapted Musical Instruments -Adapted Sexual aids -Adapted Toys -Leisure, Recreation Aids -Other -Sports Aids
Fabrication/Design								Adaptive Design/Rehab Engineering
General Equipment	General Eqt.	General Eqt.	General Eqt.		General Eqt.	General Eqt.		Other Eq.
Handicapped Signs, Sencils etc.		_						Signs, Posters, Stickers

SC SC	SIN	NM	30	TA.	M	MO	н	N.R.	INFOCTR
Home Health/Daily Living Aids	Aids to Daily Living	Home Health Aids	Home Health Aids	Home Health Aids	Daily Living - Adapted Clothing - Aids for Daily Living	Home Health/ Daily Living Aids	Home Health - Daily Living	Home Health/ Daily Living	Daily Living Aids -Eating, Drinking -Food Prepar -Grooming -Hskeeping -Other
Home/Work/Struct. Mod.(desk, ramps, elevator, etc.) Install, Build, Modify Structure	Home Modification Worksite Modifica.				Accessibility -Bidg. AccessHome AccessWorkstation -Adapted Fumiture	Home/Worksite/St ructural Mod.		Home/Work Sructural Modif.	Elevators & Lifts Eqt. Home -Bathrooms -Doors & Windows -Kitchen Appliances -Ramps -Portable & Permanent
Learning Aids/Devices					Cognitive Cognitive & Learning Aids				Cognitive & Learning -Aids, Materials -Retraining Materials
Loaned Equipment	Loan Closet			Loan Closet			Loaners	Loen	Used EqtDonation -Loan -Purchase
Medical Equipment	Medical Eqt, Non durable Medical Eqt, Dorable	Тhегару Eqt.	Medical Eqt.	Medical Eqt.		Mr. Sical Equ.	Medical Eqt.	Medical Eqt.	Medical, Therapeutic Aids
Durable Equipment Non-Durable Equipment	See Medical Eqt. See Medical Eqt.								

DS (NIS	NM	OK	LA	WI	WO	H	2. E.	INFO CTR
Mobility Aids	Mobility Aids	Mobility Aids	Mobility Aids	Mobility Aids	Mobility/Getting Around -Blind Mobility Aids -Driving & Transportation -Standing Aids -Walking Aids -Walking Aids -Wheelchairs, Wheeled Mobility	Mobility Aids	Mobility Aids		See Computer Access Mobility Aids for Visual Impmt -Accessories Standing, Walking Aids -Lifting, Climbing Devices -Other -Standing, Walking Devices
Parking Placard/License Plate		License Plates For Disabled							
Prosthetics/Orthotics	Orthotics Prosthetics	Prosthetics/Orthoti cs	Prosthetics	Prosthetics	Seating, Prosthetics, Orthotics -Functional Elec. Stimulation -Orthotic Devices -Prosthetic Devices -Seating & Positioning Aids	Prosthetics/Oπhoti cs	Prosthetics/Ort	Prosthetics/O rthotics	Prosthetics
Recreational Equipment (Adapted) See Exercise Eqt.									
Respiratory Equipment/Supplies									Respirators/Ventilators
Robotics									Robotics -Other

_				
	INFO CTR	Visual Reading Aids Low Vision Aids Page Tumers Reading Machines Specialized Glasses -Tactile Machines, Materials -Talking Products See Computer Access	Eqt. Service & Repair	Hearing Aids Conventional Specialized Television Amplifiers Adaptive Equ. Telebraillers Accesso ies Amplifiers Amplifiers Try Modems Assistive Listening Devices Group See Computer Access
	N.E.	Visual Impair	Eqt. Repair	
100000000000000000000000000000000000000	H	Sensory Aids	Spare Parts & Repair	
	MO	Sensory Aids/Braille/ Large Print	Spare Parts & Repair	
	W	Visual & Reading -Braille & Tactile Aids -Low Vision Aids -Voice/Audio Output Aids		Hearing -Alerting Devices -Assistive Listening Devices -Hearing Aids -TDD Eq.
	LA	Sensory Aids	Spare Parts & Repair Eqt.	
	OK	Sensory Aids	Spare Parts & Repair Eqt.	
	MN	Sensory Aids	Spare Parts & Repair Eqt.	
	NIS		Spare Parts & Repair	
	38	Sensory Aids - Blind	Spare Parts & Repair	Sensory Aids - Deaf
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	INFO CTR	Telecommunication Devices for the Deaf TTY/IDD Telephone Commun Aids -Adaptive EqtTelebraillers -Accessories -Amplifiers -ITY Midens			See Recreation Aids	Transfer Devices	
	NE	трБ/ПҮ Бqt.					
	н	ТЭБ/ПҮ Бф.			Toys		
	MO	TDD/ITY Eqt Closed Caption			Toys/Clothing		
	WI	Hearing -Alerting Devices -Assistive Listening Devices -Hearing Aids -TDD Eqt.			Recreation -Adapted Exercise Aids -Adapted Toys -Adapted Sponts, Leisure		
	LA	TDD/TTY Eq.			Toys/Clothing		
	30	TDD/TTY Eqt.		Tool & Machine Adapt.			
	NW	ग्रक्ट/ग्राप्त हक्.			Toys/Sports Eqt.		
	NIS				Developmental Toys		
	DS .	TDD/TTY Closed Caption Eqp.	TENS	Tool and Machine Adaptations	Toys/Clothing See Clothing-Adapted	Transfer Aids	Vehicle Restraints
ER Full Text P	YOVIDED BY ERIC	-					

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E INFOCTR	Wheelchair Accessories -Other -Standing Devices	Manual Wheeled Devices -Wheelchrs -Climbing	Adds -Reclining -Reclining -Utralite -Utralite -Strolers	Power Wheeled Reclining Devices, Wheelchairs	Power Wheeled Devices Wheelchairs	Power Wheeled Climbing Devices, Wheelchairs	Computer Access -Mobility Assistance -Other	Sensory: Hearing Assistance Sensory: Vision Assistance					
N.E.									Assessments		Adapted Devices	Device Training	Donation
IH													
т мо													
IM	See Mobility/Getting Around												
LA.													
3O.													
MM													
NIS										Animals			
SC SC	Wheelchairs									See Support Service An			

INFO CTR	Books, Bibliographies	Catalogues	Distributors	Functional Electronic Stimulation - FES Other	1 & R -Eqt	Low Tech Expressive Communication	Aids/Communication Brds	Manufacturers	Mobile Homes	Research on Eqt.	Seating & Positioning -Other
N.E.						·					
Ш											
WO											
WI											
דע											
3O											
NM											
NTS											
<u>ر</u>	1						Communication Aids				

• Developed from the Assistive Technology Service Taxonomics of the following programs:

Programs	South Carolina Services Information System (SCSIS) National Information System New Mexico Oklahorna Lousiana Wisconsin Mistouni Hawaii New England Index Information Center, Boston, MA
Abbrevlation	SC NM NM NM NM MO NM NM NM NM NM NM NM NM NM NM NM NM NM

APPENDIX E

TECHNOLOGY-RELATED INFORMATION NEEDS OF PROVIDERS AND CONSUMERS

TECHNOLOGY-RELATED INFORMATION NEEDS OF PROVIDERS AND CONSUMERS

Consumers	Service Providers
Comprehensive information and program referral services	Assistive technology-specific information and program referral services that address information needs not available at the local level
Increased public awareness on both value and application of assistive technology	Increased public awareness on both value and application of assistive technology to meet the needs of persons with disabilities
Standards to guide the confidentiality of consumer information obtained by agencies	Standards to guide the delivery of information services: data elements role of information and referral systems across levels of service delivery minimum qualifications and training of information and referral brokers
Information and referral program service staff that are trained, caring, and knowledgeable	Training for information and referral brokers
Information measures that assure the quality, accuracy, and timeliness of information provided	Lease/loan/rental program of information system hardware/software products to enhance the depth of information provided to consumers
Clear and consistent definitions for assistive technology	Training on the development, use, maintenance, and upgrading of information and referral database systems
Availability of information on quality indicator measures, e.g., Consumer Report-type ratings for assistive technology devices	Coordination of an approach for the delivery of assistive technology information and referral services
Coordination of information and referral services across communities, states, regions, and nationally	External evaluation strategies that include evaluation of programs, monitoring of program implementation plans, assessment of program ability, cost benefits analysis, and policy studies on the impact of assistive technology information and referral services
Establishment of standards that measure the effectiveness of information and referral program services	Increased funding and the designation of information and referral services as a priority equal to other services provided by agencies
Information on problem-solving strategies that allow consumers to maneuver through a complex system of services to meet their needs	Development of a consumer taxonomy for the delivery of assistive technology information and referral services



APPENDIX F

EXISTING AT I&R ORGANIZATIONAL ARRANGEMENTS

ILUSTRATION OF EXISTING AT I&R ORGANIZATIONAL ARRANGEMENTS

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Generic/ Specialized 1&R	AT Specialized	AT Specialized	AT Specialized
Geographical Area Served	National	Maryland	Iowa Minnesota
Organizational Arrangement	Decentralized network of 46 Centers with a common mission	Centralized network of regional offices that are directly accountable to the Maryland TAP	Interagency I&R subsystem of the University Hospital School at the University of Illinois providing AT services for the Iowa Program for Assistive Technology and Minnesota's STAR Program
Agency	Alliance for Technology Access	Maryland's Technology Assistance Project (TAP)	Assistive Technology Information Network
Classification of AT 1&R Service	AT I&R As A Central Focus		

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Generic/ Specialized I&R	AT Specialized	AT Specialized	AT Specialized [Prosthetics and orthotics]
Geographical Area Served	Kentucky	National	United States
Organizational Arrangement	Centralized network of 3 regional components, 1 coordinating component, and 1 research and development component directly accountable to the KATS Network	Interagency I&R subsystem operating ABLEDATA as an I&R unit within the host agency (MACRO) in which it is based	Intra-agency I&R unit that links callers to other units of the parent organization in which it is based
Agency	Kentucky Assistive Technology (KATS) Network	ABLEDATA	Resource Unit For Information and Education of the Northwestern University Rehabilitation Engineering Program
ESICalion of AT	AT I&R as a Formally Designated Service of the Agency		

Generic/ Specialized 1&R	Generic I&R	Generic 1&R	Specialized 1&R
Geographical Area Served	Kanawha, Putman, Boone, and Clay Counties of West Virginia	Nebraska	California
Organizational Arrangement	Free-standing 1&R agency operating independently and autonomously. 1&R is the single, generic service provided to its clients.	Free-standing I&R agency operating independently and autonomously. I&R is the single, generic service provided to its clients.	Interagency 1&R service operated within the Children's Hospital
Agency	Information and Referral Bureau of the Community Council of Kanawha Valley	Hotline for the Handicapped	Rehabilitation Engineering Center, Children's Hospital at Stanford
Classification of AT	Provided Upon Request		

 $\mathfrak{Q} = 1 \& R \text{ Agency}$ $\mathfrak{L} \mathfrak{G} \mathfrak{J}$

Key:

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Department of Pediatrics
School of Medicine
University of South Carolina
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